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How do adults with mild learning disabilities experience
bereavement and grief? A qualitative exploration.

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Submitted work front sheet

Declaration of own work

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ABSTRACT

Background: The vast majority of research into the experiences of people with learning disabilities (LD) in regard to bereavement and grief involves the collection of data from second-hand sources, or via quantitative measures. This qualitative study aimed to explore the lived experiences of bereavement and grief in a group of adults with mild LD.

Methods: Semi-structured interviews were carried out with 13 adults (aged 20-72 years) with mild LD who had experienced bereavement within the last 3 years. Data were analysed using interpretative phenomenological analysis (IPA).

Results: Qualitative analysis highlighted 4 themes which mediated individuals' experience of bereavement and grief: (1) Intra- and inter-personal experiences, (2) Core beliefs about life and death, (3) Level of inclusion, and (4) Continuing relationship with the deceased. Participants also showed an ability to evaluate their lived experience in terms of having been helpful or otherwise.

Conclusions: Overall, the findings suggest that individuals with mild LD experience bereavement and grief in a manner much like the general population, in that they experience a wide range of oscillating emotions, are subject to the same (if not more) losses, and hold similar values when it comes to maintaining their relationship with the deceased. The study endorses the role of clear and open communication, the facilitation of informed choice, and a culture of inclusion.

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1 INTRODUCTION

As social animals, humans will inevitably at some point in their lives experience the loss of someone with whom they shared a significant relationship. The experiences of bereavement and grief within the general population have been extensively researched. However the same cannot be said about people with learning disabilities (PWLD). To some extent, the topic of death in relation to PWLD has remained within a group of 'sensitive' topics, along with other issues such as relationships and sexuality (Lee, 1993), resulting in a lack of research relative to other, more generally accepted, subject areas. It seems that areas which may have been viewed as 'taboo' for the general population decades ago, are still seen in that light when it comes to PWLD. This has been reflected in the tendency to shield PWLD from the realities of bereavement and grief (Clements *et al.*, 2004).

In this chapter the concepts of bereavement and grief will be introduced. Next, an exploration of how psychological models of grief developed over time for the general population will be used to shed light on how equivalent understanding may be reached in relation to grief in PWLD. Looking more specifically at PWLD, manifestations of grief in PWLD will be described, along with an examination of the possible factors that impact positively or negatively upon their grief. Finally, an examination of the methodological properties of similar research in the field will be presented. This will provide justification for the methodology used in the current study.

1.1 Bereavement and Grief

Bereavement is the term used to describe the period following a loss in a person's life, in which they mourn and experience grief (Archer, 1999). Losses in life can take many forms, including loss of employment, material loss or loss of a social role (Kennedy, 1989). The type of loss discussed here is the death of someone significant. This may be a parent, sibling, partner, relative or friend.

Grief refers to the range of emotional and physical responses that an individual may experience following the loss of a loved one (Archer, 1999). The grieving period has been said to last anything between six months and two years (Parkes, 1972, 1985). However the existence of a definite timescale is controversial and appears unlikely to be established given that grief is an individual experience and not a fixed entity (Hollins & Esterhuyzen, 1997).

1.2 Understanding Grief

Often intrinsic to the experience of loss is the existence of a pre-formed relationship. Given that bereavement has been described as the most extreme form of relationship deprivation (Parkes, 2001), in understanding grief it is useful to examine the theory behind how humans form relationships in the first place. Bowlby (1977) provided a conceptual model for the human tendency to develop strong emotional bonds with others, which he termed 'attachments'. In its simplest form, attachment theory describes an infant's innate need to develop a relationship with a primary caregiver in order to have his or her physical and emotional needs met, and therefore feel safe and secure and, most importantly, survive. Bowlby theorised that a failure to develop these emotional bonds, or their breakdown, will result in feelings of

insecurity and emotional upset. Thus the basics of attachment theory provides a basis for understanding the resulting powerful emotional reaction and grief experienced in the wake of a loss like bereavement.

Attachment theory also provides an explanation for the variation observed within grieving behaviour across the human population. Although Bowlby's work on attachment theory was originally used to understand separation and loss, a secure attachment was also conceptualised as playing an additional role as a protective factor in dealing with dangerous or threatening situations (Ainsworth & Wittig, 1969). Developments in our understanding of attachment theory have led to Bowlby's core ideas being expanded into more complex models, incorporating the findings from modern developmental and neurological research (Stroebe, 2002). Newer theories focus upon how interactions with attachment figures in early life and the resulting emotional experiences affect the maturation of the brain, particularly the neural systems that control self- and affect-regulation (Schore & Schore, 2008). Schore (1994) incorporated neurobiological theory by demonstrating the role that attachment communications play in the development of right-brain systems such as emotion processing, stress modulation, self-regulation and therefore the basis of one's human 'self' (Schore, 2003). Neurological studies into the effects of early trauma and neglect show that the brains of such poorly attached individuals experience changes in their neurochemistry and brain organisation, and that this has long-lasting effects on how individuals react to stress in their later lives, thus affecting their life-long mental health (Parkes, 2001; Schore & Schore, 2008). Also, links have been made between insecure attachment styles and later difficulties with the grieving process (Parkes, 2001; Shaver & Tancredy,

2001). Thus, a secure attachment can be said to be protective in dealing with general stressors in later life such as bereavement, by means of its influence upon the development of coping strategies (Bowlby, 1988), and the nature of one's attachment relationship may influence how the subsequent breaking of that attachment bond is experienced.

Grief has been shown to vary in its manifestation depending on the nature of the original attachment relationship. Normand *et al.* (1996) found that when comparing grief responses among parent-bereaved adolescent college students, those with less emotional attachment to the deceased had lower levels of depression, less intrusive thoughts about the deceased, and did not feel the need to avoid reminders of the deceased. This suggests that there is a link between level of attachment and grief experience. However this study did not define participants' attachment styles in terms of being secure or otherwise and so the conclusions are limited in relating to extent of attachment and do not extend to specific attachment styles.

Regarding the link between attachment style and coping with bereavement, Wayment and Vierthaler (2002) carried out a large study in which attachment to the deceased and grief reaction were compared in a sample of 91 adults. Those with a secure attachment to the deceased reported higher levels of grief, but were less likely to become depressed. On the other hand, those with less secure attachment styles were more likely to have maladaptive reactions, becoming depressed and exhibiting somatization. This suggests that attachment affects one's grief experience by influencing quality of mental health following bereavement. It is worth noting however that this study also compared variables such as global attachment style (i.e.

not specific to the deceased), and suddenness of the death, showing the role other individualised factors play within the grieving process.

Thus, grief can be said to be a complex and variable experience that must be understood in the context of individual differences. Attachment is only one example of a framework within which to account for these differences. Given the continuum of possible grief experiences it is not surprising that there is much debate in the literature on what constitutes 'normal' (also known as adaptive) grief, and 'abnormal' (also known as maladaptive, pathological, complicated, unresolved, morbid) grief (Middleton *et al.*, 1993; Raphael & Minkov, 1999). Manifestations such as extended mourning periods, presence of auditory and visual hallucinations, and somatization, to name a few, are still to be definitively categorised either way.

1.2.1 Models of Grief

Much development and critique of psychological models over time has led to our current understanding of how the general population experience grief. In fact, despite decades of research in the field, there is yet to be established one accepted model of what constitutes a normal grieving process. Given the comparatively early stages of research into grief in PWLD, the main theoretical milestones in grief theory development in general will now be described, so as to shed light upon how grief in PWLD may subsequently be understood.

1.2.1.1 Staged Models of Grief

Many of the early grief models take the form of 'staged models'. These consist of various predictable phases said to be experienced over time through the process of accomplishing various tasks.

Freud (1917) was the first to identify consistently observed features of human grief:

- profoundly painful dejection;
- cessation of interest in the outside world;
- loss of capacity to love; and
- inhibition of all activity. (Freud, 1917)

Freud saw relationships as an investment of energy into love objects that, in turn, satisfy needs and provide an outlet for emotional expression. This investment, that he termed 'cathexis', is comparable to Bowlby's attachment bonds. According to Freud, bereavement leaves an individual in the position of trying to regain that energy by attempting to maintain an active bond with the lost loved one. Of course, the death of a loved one makes maintaining the same relationship with them impossible, and according to Freud, it is breaking one's bond with the deceased, adjusting to life without them, and forming new relationships that are the essential tasks for achieving a positive grief outcome. Freud termed the process of arriving at this realisation, by means of repetitive reality testing, 'grief work'. This is the earliest reference to grief involving 'work' of some kind or requiring the completion of an effortful process.

Freud's emphasis on the need to break all bonds with the deceased resulted in criticism of his theory. Some argued that it is precisely the ability to maintain a workable bond with a lost loved one that predicts coping

(Conant, 1996; Klass *et al.*, 1996). Further, it has been argued that Freud's model paints grief as a solitary occupation and does not account for the role that the support of a good social network provides, or the benefits of expressing one's grief to others (Bowlby, 1980).

Lindemann's (1944) model of grief built on the foundations of Freud's theories. He noticed that temporary behavioural and emotional changes were common following bereavement. He concluded that, given their generalised manifestation, these symptoms of grief should not be pathologised or labelled as abnormal. He identified five normal grief reactions:

- somatic distress;
- preoccupation with the image of the deceased person;
- guilt;
- hostile reactions; and
- the loss of patterns of conduct (Lindemann, 1944)

Lindemann was the first to acknowledge that grieving can vary in its intensity and duration. By acknowledging the effect on an individual's 'patterns of conduct' he also took into account the effect that grieving may have upon one's social functioning.

However, Lindemann's work received criticism due to the samples upon which he based his theory. His studies were predominantly carried out on individuals who were either undergoing psychiatric treatment or had been bereaved as a result of disaster and war. Critics contested that he may therefore have been reporting on cases of post-traumatic stress disorder, rather than the typical grief reactions that could be expected within the

general population (Klein & Alexander, 2003). Conversely, it could be argued that not all bereavements experienced by the general population are non-traumatic or expected in nature. They may not all result from natural disasters or warfare, but accidents, unexplained deaths, and acute illnesses do occur. Thus it could be argued that to experience bereavement in any form constitutes a form of traumatic event (Stroebe *et al.*, 2001).

Furthering the focus upon the social aspect of bereavement, Parkes (1988) formulated bereavement as a 'psychosocial transition'. He suggested that the loss experienced in bereavement threatens an individual's internal model of the world, challenging their assumptions of 'routine patterns of interaction' (Payne *et al.*, 1999, p.67). According to Parkes' theory, when our assumptions are fulfilled we experience security and contentment. Conversely, the distress of grief occurs as we strive to develop new ways of relating to the world, in the absence of the deceased. Parkes' suggestion that grief work entails adjustment to novel circumstances echoes Freud's notion of reality testing in the wake of bereavement.

The concept of there being an adjustment aspect to the grieving process formed the basis for Worden's (1983) grief model. He also viewed grief as a process, and specified four discrete stages. His model, however, allowed for greater flexibility in reaction, in that phases could manifest in any order, and be of varying duration. Worden's four stages, termed the 'tasks of grieving', are

- to accept the reality of the loss;
- to process the pain of grief;
- to adjust to a world without the deceased; and

- to find an enduring connection with the deceased in the midst of embarking on a new life. (Worden, 2009)

Along with the emphasis on the psycho-social aspect, Worden also introduced the importance of cognitive and behavioural aspects of grief. He incorporated stress theory (Horowitz, 1986) into his model and focussed upon the emotional and intra-psychic effects of loss; anxiety, searching behaviour, anger and guilt. His was the first stage model of grief to place the bereaved in an active role (responding to grief in an organised manner, rather than simply reacting to circumstances that they cannot control), thus creating an opportunity for grief-work-based interventions.

Marris (1992) provided another viewpoint on grief by being the first to suggest that successful grief does not require the complete severance of emotional ties with the deceased. His model subscribed to the thus-far popular theme of grief work entailing adjustment to a new reality by classing the manifestations of grief as symptoms of an interim state of emotional flux while such adjustment is made. However, Marris saw successful grieving involving extraction of what was important about the relationship, deduction of its meaning, and having a continued sense of its importance in their new reality. This maintenance of the relationship's importance into the bereaved's future life could explain the tendency for humans to adopt mourning rituals, such as the cherishing of sentimental reminders of the deceased and continued commemoration of their life.

Thus stage models of grief share a sense of grief being a process that is worked through by means of the completion of phases, but there is some

disagreement in terms of what becomes of the relationship with the deceased; whether it is severed and left behind, or continues to hold meaning, albeit in a form compatible with one's new lived experience, and new and continuing relationships (Klass *et al.*, 1996).

1.2.1.2 Criticisms of Staged Models of Grief

The main criticism of a staged model of grief is that the complex nature of grief cannot be accounted for so simplistically by predictable stages and tasks (Maciejewski *et al.*, 2007). Critics disapprove of the tendency to use such staged models prescriptively, thus denying the diverse range of possible grief reactions reflected both in clinical experience and in the research literature. In fact such a prescriptive view of grieving is blamed for the over-diagnosis of pathological grief which occurs when an individual's grief reaction does not 'fit' with the set phases or tasks (Stroebe *et al.*, 1993).

Wortman and Silver (1989) conducted a review of the existing literature at the time and found that much of the available empirical evidence on grief reactions did not support, and in some cases even contradicted, the patterns suggested by stage models. For example, they challenged the consistent inclusion of a stage of emotional instability, countering that distress and depression are not inevitable following bereavement. They quoted several studies that showed bereaved individuals suffering depression to be in the minority (Clayton *et al.*, 1972; Lund *et al.*, 1986), and that the presence of depression is more likely to predict a poorer outcome (Lund *et al.*, 1985; Vachon *et al.*, 1982). Parkes (1996) went on to counter-argue that in fact Wortman and Silver had confused distress with depression and held firm to the idea that individuals from all cultures react to bereavement in some

manner. However he did concede that the nature of the lost relationship may temper such distress, for example in the case of little or no attachment bond.

Further criticism identifies issues with the assumptions intrinsic to the concept of 'grief work' present in stage models. This assumes that, if worked through 'correctly', grief is not an indefinite process, and an individual should 'recover' from grief. Often, it is a failure to adequately 'recover' in this way that attracts the label of 'pathological grief', implying a negative outcome (Bowlby, 1961; Osterweis *et al.*, 1984; Raphael, 1985). Wortman and Silver (1989) pointed out the audacity of this assertion, given the reluctance of those same theorists who specified the relevant stages to specify a precise timescale for successful recovery, citing suggestions ranging from 4 weeks to seven years (Lehman *et al.*, 1987; Lindemann, 1944). They also cited several studies that showed that up to 2 years post-loss, the bereaved were still asking questions such as "Why me?" and making statements like "It's not real", thus suggestive of an on-going search for resolution (Parkes & Weiss, 1983; Wortman & Silver, 1987). Further there is evidence that suggests that those who engage in less 'grief work' in the form of active mourning are those who, in the long-term, have the best grief outcome (Parkes & Weiss, 1983; Vachon *et al.*, 1982).

1.2.1.3 Newer Models of Grief

Taking into account the criticisms levelled at staged models, more recent theories have seen a departure from this formula into the development of more flexible models of grief. Newer models of grief incorporate more sympathetic and dynamic psychological processes, whilst acknowledging the wider systemic impacts bereavement can have.

Dual process theory, for example, highlights not only the expression of grief, but also the avoidance and control of reactions. It stresses the importance of the bereaved accomplishing a balance in oscillating between the expression of grief while simultaneously adjusting to a new reality. Stroebe & Shut (1995) termed these two activities 'loss orientation' and 'restoration orientation'. Loss orientation refers to grief behaviours such as ruminating, yearning and using reminders of the bereaved, while restoration orientation encompasses making lifestyle adjustments in the deceased's absence.

Restoration orientation can be further broken down into four suggested tasks:

- taking time off from the pain of grief;
- mastering the subjective environment in which the deceased is missing;
- developing new roles and relationships; and
- accepting the reality of the changed world. (Stroebe & Schut, 1999)

The dual process model allows for more flexibility in the manifestations of grief by acknowledging the possible individual differences dependant on the circumstances of the loss, personality factors, gender and cultural background, while not imposing stage-specific time scales or consecutiveness (Dent, 2005).

Other suggested theories have recommended the acknowledgement of the systemic impact of bereavement, rather than focussing solely on the impact upon individuals (Dent, 2005; Kissane & Bloch, 1994). Systemic theories take into account the effect upon the whole family and the related influences that

inhibit or enhance the experience of grief and bereavement. This is an important perspective to consider when thinking about grief in PWLD, given the extensive systems such individuals tend to be part of.

It is clear then that grief is, through its widespread presentation, a normal response to loss and should not be pathologised as a 'disease' (Clegg & Lansdall-Welfare, 2003; Kopelman, 1995). Certainly, there exists no shortage of available frameworks within which to interpret grief and the nature of the empirical evidence that lies behind these theories. These frameworks have changed and evolved over time in order to better fit with the lived experiences of bereaved individuals as discovered through investigative research. While this thesis does not aim to recommend one model above another, in the absence of equivalent conceptualisations of grief specific to PWLD, it presents them as possible contexts within which to interpret the experiences of PWLD following bereavement.

1.3 Terminology

For the purpose of this thesis, the term 'learning disabilities' (LD) will be used throughout. The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) states three generally accepted criteria that must be met for the diagnosis of LD. These are:

1. an intelligence quotient (IQ) of less than 70;
2. significant difficulties in two or more areas of adaptive functioning;
and,
3. onset before the age of 18 years (American Psychiatric Association, 1994).

The International Classification of Disease (ICD-10) (World Health Organisation, 1992) further provides the descriptive terms of 'mild', 'moderate', 'severe', and 'profound' to specify levels in the continuum of cognitive ability from more to less able.

1.4 Do PWLD Experience Grief?

Over the years, and especially in the earlier literature, it has been questioned whether or not PWLD experience grief in the same way as the general population, if at all (Nagera, 1970; Wolfenstein, 1966). Some have suggested that, should they grieve, PWLD are sure to do so abnormally (Dowling *et al.*, 2006). These hypotheses have arisen due to the assumption that PWLD lack the ability to develop meaningful relationships (attachment) and understand loss (death concept).

1.4.1 Hypothesis 1: Difficulties with Attachment

Given the aforementioned link between attachment and grief it was assumed in the early literature that PWLD have difficulty forming meaningful attachment relationships and are thus shielded from experiencing grief (Burlingham & Freud, 1942; Freud, 1917). Suggested reasons as to why PWLD would have higher levels of insecure attachments included deficits in social functioning as well as systemic factors such as the initial effect their diagnosis has upon the attachment relationship with their parents, the high turnover of care staff preventing the formation of long-term relationships, and the limited opportunities provided by society for expanding their social networks (Esterhuyzen & Hollins, 1997; Hodges & Tizard, 1989; Tizard & Hodges, 1978; Todd *et al.*, 1990).

However, these reasons overlook the dynamic nature of attachment bonds. They are not the result of a one-way interaction but rather are reliant upon both partners in the relationship being invested in each other (Solomon & George, 1999). Research has also shown that level of intelligence, and therefore ability to function socially, does not necessarily predict the ability to form attachments. For example, much research has been carried out investigating the ability of new-born babies (whose brains and intellect are at the earliest stages of development) to form attachments with their caregivers. Infants as young as a few hours old have been shown to have preferential eye-gaze towards their main carer, and display reciprocal emotional and expressive behaviours (Anderson, 1972; Niven *et al.*, 1993; Schaffer & Emerson, 1964). Attachment relationships have also been demonstrated in a range of animals including primates, rodents, and dogs (Kraemer, 1997; Mendoza & Mason, 1997; Pettijohn, 1979). These findings fit with the attachment theory posited by Bruner (1990) who stressed the biological and cultural aspects of attachment development. He described attachment as a pre-determined aspect of human nature that is biologically driven and creates innate behaviours that precede any cultural influences, and are therefore a natural part of being human.

Much of the recent research into attachment styles in PWLD makes links between insecure attachment relationships and the prevalence of challenging behaviour (Janssen *et al.*, 2002). Challenging behaviour can be accounted for by attachment theory in two ways. Firstly, according to the stress- or affect-regulation model of attachment, it is suggested that, having missed out on the regulatory function provided by secure infant/attachment-base interaction, PWLD fail to reach a mature level of emotional development that

allows them to maintain an emotional homeostasis and confidently explore their world (Clegg & Lansdall-Welfare, 1995). Secondly, it can be reasoned that due to their disorganised attachment style, PWLD are more likely to have difficulties managing their social relationships, either becoming over-invested in individuals, resulting in feelings of jealousy, or by demonstrating ambivalence towards relationships and thus rejecting social contact (Clegg & Sheard, 2002; De Schipper & Schuengel, 2010).

Therefore while it may be true that PWLD have more difficulty forming attachment relationships in the same manner, and to the same extent as the general population, and may be more likely to develop attachments that are insecure in some way, it is clear that attachment and relationship development are not out with the scope of PWLD, making them just as open to experiencing grief (Clegg & Lansdall-Welfare, 1995; Esterhuyzen & Hollins, 1997; Frankish, 1989, 1992; Hawes & Hollins, 1997).

1.4.2 Hypothesis 2: Difficulties with Developing a Death Concept

It has been suggested that in order to recognise a loss and subsequently grieve, one must first understand the concept of death itself. In turn, it has been suggested that in order to have a true understanding of death, one must comprehend several distinct concepts (Nagy, 1948; Speece & Brent, 1984).

These are

- finality (death is irreversible);
- non-functionality (the cessation of bodily processes);
- causality (death has objective causes); and

- universality (death is inevitable). (Adams & Deveau, 1995)¹

It has been argued that PWLD are unable to experience grief based upon the assumption that their cognitive deficits render them unable to understand these concepts, and thus the concept of death itself (Hughes & Noppe, 1985; Speece & Brent, 1984). This hypothesis assumes that level of cognitive functioning is directly proportionate to level of understanding of death, with a higher level of cognitive functioning being indicative of a better understanding of death (Mayreddi & Narayan, 1993).

In support of this theory, through the use of structured interviews about death, McEvoy (1989) found that the concepts of finality and non-functionality are better developed in PWLD functioning at a higher cognitive level. He also found that having an awareness of one's own mortality predicts greater understanding of death in general, while the concept of universality was found to be the least well developed. McEvoy's methodology did not include a standardised measure of cognitive ability and so it is difficult to allocate his findings to one particular cognitive ability level. However the participant characteristics described (the ability to answer questions verbally and generally high levels of social competence) are suggestive of participants with higher levels of cognitive functioning (mild/moderate LD).

Level of cognitive functioning may also predict understanding of the concept of causality of death. PWLD functioning at a higher cognitive level have been

¹ It is important to note that the extent of belief in these concepts may differ across cultures (Cowles, 1996).

shown to be more likely to identify possible abstract causes of death such as old age and alcohol abuse rather than more concrete explanations such as specific illnesses or accidents (Mayreddi & Narayan, 1993). This suggests that intellect predicts the ability to identify a wider range of causal factors, especially those which are not clearly attributable to external factors.

Because of their developmental level, comparison is often made between the abilities of children and those of PWLD (Bihm & Elliott, 1982). In light of this, Nagy (1948) described children having a 3-stage concept of death, starting with the idea of “being asleep”, aged 3-5 years; personifying death as a skeleton, ghost or “bad man”, aged 5-9 years; and developing the full concept as described above by age 9. It is worth bearing in mind that this may simply reflect the maturation of vocabulary with age, rather than the complexity of concept held.

It may not be as simple as inferring the experiences of PWLD from those discovered in children as differences in processing have been highlighted. For example, McEvoy (1989) proposed that PWLD tend to see death in very ‘black and white’ terms: as an externally influenced process or something that happens *to* you. They are more likely to state accident or disease as causes of death. On the other hand, children, from as young as seven years of age, develop the understanding that death can be an inevitable internal biological process, governed by the laws of nature or ‘circle of life’.

This would suggest that developmental stage is not the only factor responsible for the development of the concept of death. Moreover, other factors aside from level of cognitive functioning have been found to influence

level of understanding of death. For example, older PWLD have been shown to have a better understanding of the concept of death, thus showing the influence of chronological age (Seltzer, 1989). This may be due to having more exposure to bereavement due to increased life experience (Patja *et al.*, 2000), thus having greater opportunity to experience life events such as bereavement. One study carried out during a time of civil unrest found those functioning at a lower cognitive level were more likely to report bombing, gunshot wounds, stabbing and murder as a likely cause of death (Myredden & Narayan). It was thought that this was due to media coverage of recent violent events impacting upon one's development of death concept. Environment, therefore, also seems to play a role in the development of the death concept (Kastenbaum & Costa, 1977).

These two hypotheses also assume that PWLD can be classed as one homogenous group, ignoring the existence of individual differences in abilities. Interestingly, irrespective of level of understanding and maturity of death concept, Harper & Wadsworth (1993) concluded that level of conceptual understanding in no way predicts the ability of an individual to feel the emotional impact of bereavement or display emotional behaviour. So although cognitive ability may influence one's intellectual understanding of death and its consequences, this suggests then that the emotional experience of grief is universal to all individuals regardless of their level of cognitive functioning, and that PWLD are no more exempt from the experience of grief than the general population. How this is demonstrated by way of manifestations of grief will now be described.

1.5 Grief in PWLD

It was previously thought that PWLD were unable to experience feelings of grief following bereavement (Hollins & Kloeppel, 1989). There now exist a number of case studies, qualitative interviews and population studies that show that PWLD do exhibit behaviours that could be interpreted as manifestations of grief (Bonnell-Pascual *et al.*, 1999; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Hollins & Kloeppel, 1989; McLoughlin & Bhate, 1987; Reid, 1972; Singh *et al.*, 1988; Yapa & Clarke, 1989). A systematic review carried out in 2005 found 27 articles describing the effects of bereavement in PWLD (Dodd, Dowling *et al.*, 2005). These were found to be emotional, behavioural and psychiatric in nature.

1.5.1 Emotional Manifestations

PWLD have been shown to experience a range of emotional effects as a result of bereavement including sadness, anger, anxiety, distress, confusion and pain (Harper & Wadsworth, 1993; Strachan, 1981). PWLD have themselves described bereavement as “distressing” and “disruptive” (Harper & Wadsworth, 1993; Strachan, 1981).

In their study, Hollins and Esterhuyzen (1997) compared the emotional responses of 50 PWLD who had lost a parent with that of 50 non-bereaved peers. They found that those in the bereaved group experienced higher levels of anxiety, depression and irritability. A study by MacHale and Carey (2002) identified similar patterns, including increased lethargy and moodiness in bereaved individuals.

1.5.2 Behavioural Manifestations

These studies also revealed behavioural manifestations of grief including increased hyperactivity and inappropriate speech, and increased prevalence of crying (Hollins and Esterhuyzen, 1997; MacHale and Carey, 2002)

For PWLD, emotional upset can often be reflected in increased levels of challenging behaviour (Day, 1985). In the previously mentioned study by McHale and Carey (2002) 90 per cent of the individuals who had experienced bereavement displayed challenging behaviour, as opposed to only 38 per cent of non-bereaved individuals. Unfortunately this study did not include a premorbid measure of levels of challenging behaviour and so it can only be assumed that the difference in incidence is due to bereavement, and the resulting grief reaction. However, evidence of behavioural change is backed up by the findings of several other studies (Day, 1985; Emerson, 1977; Harper & Wadsworth, 1993). A study by Conboy-Hill & Waitman (1992) found that grief can predict and intensify behavioural difficulties such as elective mutism, self-injurious behaviour, anorexia, incontinence and aggression.

1.5.3 Psychiatric Manifestations

It is generally accepted that PWLD have an increased risk of comorbid mental health problems for reasons that have yet to be firmly established (Smiley, 2005). Estimates of the prevalence of mental health problems in PWLD vary widely due to inconsistent diagnostic criteria of both psychiatric problems and LD itself, along with unreliable measures (Dodd, Dowling *et al.*, 2005; Smiley, 2005). Estimates of overall prevalence of mental health problems in PWLD range from between 14 and 70 per cent (Bregman &

Harris, 1996; Cooper, 1997; Cooper *et al.*, 2007; Corbett, 1979; Deb *et al.*, 2001; Eaton & Menolascino, 1982; Lund, 1985).

Bereavement and grief are established predictors of mental health problems in the general population (Jacobs & Kim, 1990). For example, grief is associated with increased risk of anxiety, depression, hallucinations, and dysphoria (Bruce *et al.*, 1990; Byrne & Raphael, 1997; Clayton, 1990; Grimby, 1993; Zisook *et al.*, 1994). There is also evidence of increased incidence of somatic difficulties, suicide and mortality (Duberstein *et al.*, 1998; Kaprio *et al.*, 1987; Lannen *et al.*, 2008; Rogers & Reich, 1988).

Although the link between bereavement and mental health problems in PWLD remains under-researched, studies have shown that PWLD who experience bereavement are more likely to experience mental health problems than bereaved individuals of the general population (Nadarajah *et al.*, 1995). Just as in the general population, bereaved PWLD have a higher incidence of depression, mania and psychosis (Harper & Wadsworth, 1993; Hollins & Kloepfel, 1989; Yapa & Clarke, 1989). Links have been shown between PWLD experiencing a parental bereavement and a resulting decline in mental health (Dodd, Dowling *et al.*, 2005; Hollins & Esterhuyzen, 1997). This may reflect the extended role that parents often play in the life of a child with LD (Beresford, 1994). Bereavement has been said to account for around half of all psychiatric hospital admissions in PWLD (Day, 1985).

Thus, having considered a range of typically recognised manifestations of grief, it appears that PWLD grieve in a manner very much like that of the general population (Harper & Wadsworth, 1993; Meyers, 1980; Oswin, 1991).

The fact that these results are found across all levels of LD suggests that, while their experience may differ qualitatively depending on the extent of their understanding, cognitive impairment does not in itself prevent the experience of grief (Brelstaff, 1984). Factors that contribute to higher levels of emotional, behavioural and psychiatric difficulties will now be explored.

1.6 Difficulties Specific to PWLD

Evidence suggests that PWLD are likely to experience complications during the grieving period over and above those typically experienced by the general population. It is thought that these additional difficulties are due to several systemic factors; that of secondary losses, communication problems, difficulties with tasks of grieving, and issues around inclusion.

1.6.1 Secondary Losses

Bereavement typically brings with it changes to the lives of the bereaved. Many of these changes will take the form of additional losses of some kind. These types of losses are referred to as secondary losses because they are secondary to the circumstances of the original loss (Rando, 1993).

Perhaps the most immediate secondary loss for PWLD can be the loss of their primary carer (Scottish Executive, Health Department, 2000). With the recent move towards reducing the institutionalisation of PWLD, individuals are now more likely to be cared for within the community, and many carers are family members, such as parents or siblings (Scottish Executive, Health Department, 2000). This has generally been a positive change in integrating PWLD into society but it comes with its own challenges also. For example, in a study in 1993, Farmer *et al.* found that, due to global population changes

there are more elderly carers now than ever before, and this number continues to rise. This brings with it a higher likelihood that those cared for will experience the loss of their carer in death, whether through old age or old age-related illness.

A study by Hollins & Esterhuyzen (1997) sampled 50 bereaved PWLD. They found that for 30 per cent of their sample the bereavement constituted the loss of their last remaining family carer. For the remaining 70 per cent, the majority had co-habited with the deceased, or the deceased had been either one of their main carers, or someone whom they saw regularly. In what can already be a reduced social network this can have a magnified impact for PWLD in terms of loss (Thorpe *et al.*, 2000). Even if the main carer is not a parent, some have compared the loss of a main carer to that of a child losing a parent in terms of the type of attachment relationship lost, and the resulting emotional impact (Clegg & Lansdall-Welfare, 2003). The deceased may have been one of few people able to understand and translate the individual's method of communication. They may have been the person most familiar with the individual's medical history and care needs. The knock-on effects and potential for subsequent losses are substantial (Brickell & Munir, 2008).

Often intrinsic to the loss of a caregiver is a change in residential accommodation. Again, this is increasingly likely with less institutionalised care. Studies have found that between 40 and 90 per cent of PWLD who experience bereavement then experience the secondary loss of their home (Hollins & Esterhuyzen, 1997; MacHale & Carey, 2002). This may entail moving out of the family home, or having to move to a different geographical region. Some may go on to face a series of moves; reportedly as

many as five within the period of one year (Oswin, 1991). It could be that a proportion of these successive moves result from difficulties in dealing with the manifestations of the individual's grief and the resulting breakdown of residential placements. Harper & Wadsworth (1993) identified several other types of secondary loss reported by PWLD: less or no visitors; less daytime activities; a change of roommate; less money; losing a job; and, a change in legally appointed guardian. Certainly then it can be said that for PWLD a bereavement involves not only the loss of the deceased but also involves a wider impact upon their lives.

1.6.2 Communication Problems

Communication plays a large role in the lead up to, and following bereavement. Studies have shown that both emotional and informational communication help in the processing of grief in children (Saldinger *et al.*, 2004). This entails being given age- and intellect-appropriate information about the likely death of an important person and what it will involve, as well as being given a space to express one's grief to others who listen effectively. Similarly, the provision of such information to PWLD is thought to be beneficial (Oswin, 1991).

However research suggests that communication with PWLD around bereavement and grief tends to be insufficient. It may be that the individual themselves is unable to express his or her grief successfully due to communication difficulties intrinsic to their disability, or that those around them may be unwilling to hear what they have to say, or facilitate their communication appropriately (Focht-New, 1996). Unfortunately this lack of communicative outlet leads many carers to incorrectly believe that PWLD

have been unaffected by the bereavement (Hollins & Esterhuyzen, 1997; Strachan, 1981). Even when there are observed behavioural and emotional changes these are more likely to be attributed to their disability rather than grief by both carers and professional healthcare staff (Reiss *et al.*, 1982).

Studies assessing carer knowledge and skills in dealing with bereavement in the individuals with LD whom they care for show a general lack of knowledge and confidence. Carers have reported feeling that they do not have the skills required for tackling the subject of grief or, having had appropriate training, feeling a lack of confidence in their ability to put such training into practice (Dodd, McEvoy *et al.*, 2005; Dowling *et al.*, 2006; Murray *et al.*, 2000). They have also reported believing that if they broach the subject of grief the individual will require a level of support that exceeds that which they feel able to provide (MacHale *et al.*, 2009).

In line with these findings many studies have identified a trend towards a 'conspiracy of silence' between carers and family members in relation to informing PWLD of the death of a loved one, and in dealing with resulting grief (McLoughlin, 1986; Murray *et al.*, 2000; Oswin, 1991). This is often out of fear of upsetting the individual and in the hope that the loss will go unnoticed (Crick, 1988; Dowling *et al.*, 2006; Kennedy, 1989; Seltzer, 1985). Some individuals may never be informed of a death (Bicknell, 1983; Oswin, 1991). In the aforementioned study by Hollins & Esterhuyzen (1997) it was found that nearly 65 per cent of PWLD interviewed had not discussed the impending loss with anyone before the event. This may in fact be an underestimation, seen as only 30 per cent of individuals had an identified member of staff tasked with ensuring notification was carried out. For 20 per

cent of the sample none of their carers could confirm whether they had been informed or not.

Some suggest that, even if the lines of communication are open, carers may not be best placed to provide support due to the complexity of the carer/service user relationship and the boundaries each side must observe (Murray *et al.*, 2000). In fact, the carer themselves may be grieving and thus be unable to provide adequate support due to their own distress (Moore, 1992). Thus it seems that, while openness in communication is beneficial it is an aspect of bereavement fraught with reluctance and other obstacles.

1.6.3 Tasks of Grieving

As cited earlier in describing the various available models of grief, many theorists believe that in order to work through and resolve one's grief one must accomplish certain tasks of grieving. The available literature suggests that PWLD will experience additional difficulties in completing these tasks due to features intrinsic to their disability.

One such task of grieving is that of finding meaning (Neimeyer, 2002). This refers to an individual 'relearning' themselves and the world around them in the context of no longer having the deceased in their life (Attig, 1996; Saldinger *et al.*, 2004). It has also been described as finding a 'narrative' that articulates and contains one's grief, and finding 'benefit' in discovering purpose in one's own life following a loss (Davis *et al.*, 1998; Janoff-Bulman & Frantz, 1997; Neimeyer, 2002).

Further research is needed to establish whether or not there is a link between cognitive ability and the ability to find meaning following bereavement. Research in the general population is inconclusive; some claim that finding meaning is an essential part of the grieving process, while others suggest individuals who never find meaning in this way suffer no adverse effects and that the inability to complete this stage of grief work is problematic only when a desire to find meaning goes unfulfilled (Davis *et al.* 1998; Neimeyer, 2002).

Some have suggested that PWLD will find this sort of task more difficult, especially that of finding benefit. It has been suggested that PWLD are unable to find meaning due to the intellectual concepts and abstract reasoning involved, and due to their typically dependent position within society and the resultant lack of opportunities to grow and change (Brickell & Munir, 2008). There are also implications for the implementation of well-meant strategies and administration of medication in that these may inadvertently prevent an individual from being able to adapt and develop new coping strategies that would otherwise be protective in the case of future losses (Moise, 1985).

1.6.4 Inclusion in Rituals

In the general population, the practising of bereavement-related rituals has been proven to be helpful in resolving grief (Stroebe *et al.*, 1993). Rituals vary widely dependant on cultural influences but may include practices such as viewing the body of the deceased, holding a funeral, and visiting resting places. However views on who should participate in such rituals vary. For

example, children are often sheltered from the strong emotions seen at funerals (Clark & Clark, 1993).

Studies of the involvement of PWLD in rituals show a similar wariness regarding inclusion. Levels of funeral attendance in PWLD have been measured at around half (Hollins & Esterhuyzen, 1997; Oswin, 1991). The reason most commonly cited among third parties for discouraging PWLD from attending a funeral is the fear that the experience will be “too upsetting” for the individual (Hollins & Esterhuyzen, 1997). In one study 16 per cent of bereaved PWLD were not informed of the death until after the funeral, thus removing the possibility of attendance (Harper & Wadsworth, 1993). Yet PWLD have themselves reported that they find inclusion in rituals helpful (Gilrane-McGarry & Taggart, 2007). An area which seems to have higher levels of participation in PWLD is the ritual observances that follow a funeral. MacHale and Carey (2002) found that 70 per cent of PWLD involved in their study had mementos of the deceased, while 65 per cent visited the grave of the deceased on a regular basis.

For PWLD ritual involvement is thought to aid their understanding of death (Raji *et al.*, 2003). It also allows individuals to normalise their emotional experience of grief as they observe how others mourn (DeRanieri *et al.*, 2002). Supported involvement has been shown to reduce both repetitive questions about the whereabouts of the deceased, and the frequency and intensity of challenging behaviour (Sheldon, 1998). Others have found that, if managed poorly, ritual involvement can result in more problematic grief, thought to be due to insufficient preparation beforehand or explanation and communication following (Dodd, McEvoy *et al.*, 2008). This is reiterated by

Clegg and Lansdall-Welfare (2003) who stress that involvement alone is not sufficient and that, for participation to be beneficial, a generalised culture of emotional support is required.

It is clear then that for PWLD bereavement and grief for PWLD may have added complications. Depending on their manifestation, some theorists would class such difficulties as evidence of 'abnormal' responses or pathological grief (Bonnell-Pascual *et al.*, 1999; Brickell & Munir, 2008). It is outside the remit of this thesis to enter into the normal/abnormal grief debate given that this study is exploratory in nature. Rather, the researcher seeks to shed light upon the grieving experiences of PWLD, irrespective of their adaptive or maladaptive function.

1.7 Characteristics of the Literature

In order to sample the pre-existing literature on bereavement and grief in PWLD and to explore any equivalent studies, the relevant literature was considered, much like a 'narrative literature review' (Baumeister & Leary, 1997). This involved the identification of relevant studies, the consideration of their methodologies and findings, and the drawing of relevant conclusions. It is worth noting at this point that, within the remit of this thesis, this process was not intended to equate to a full systematic review, but rather to make transparent the researcher's reasoning in identifying the need for a research study utilising the current methods.

A search for studies with similar aims to the current study was carried out. The search method used various terms related to LD, in combination with various grief-related terms, as shown in Table 1.

Table 1: Literature search terms

Learning disab* ²		Bereavement
or		or
Intellectual disab*		Grief
or		or
Mental retardation	and	Grieving
or		or
Developmental delay		Death
or		or
Developmental disab*		Loss

² * denotes the use of the truncation function.

The search terms were used in the 'title' and 'main body' fields of the following databases:

- Ovid MEDLINE (R) 1980 to 1987
- Ovid MEDLINE (R) 1988 to 1995
- Ovid MEDLINE (R) without Revisions 1996 – February Week 2 2011
- British Nursing Index and Archive 1985 to February 2011
- EMBASE 1980 to 2011 Week 07
- PsychINFO 1987 to February Week 3 2011

This resulted in a total of 210 articles. An initial scan of abstracts to remove any articles not directly related to bereavement and grief in adult with LD resulted in 76 articles. Articles related to the development of assessment tools or interventions were then removed due to the exploratory nature of the research question. Book reviews, dissertation abstracts, meta-analyses, case studies and any articles specifically concerned with abnormal grief were then removed, as were articles whose aim was not to provide new data on the experience of bereavement and grief in PWLD. This resulted in 10 relevant studies³.

1.7.1 Methodological Review

All 10 of the studies identified stated aims related to exploring the bereavement experiences of PWLD. The methodological properties of the 10 identified studies are shown in Table 2.

³ The identified papers were not subjected to a quality assessment framework, and this should be borne in mind in relation to the interpretation of the described research.

In exploring the existing literature related to bereavement and grief in PWLD the most striking observations are the tendencies for researchers to a) use quantitative methods; and b) obtain their data from sources other than the individuals with LD themselves.

Three of the 10 studies clearly stated that their aim was to assess the knowledge or opinions of those other than the PWLD themselves, be it the care provider, carers, or parents. The aims of a further three studies were unclear as to their target population. The remaining four studies all had aims that implied the direct assessment of PWLDs' personal experience, using phrases such as "...studying the experiences of...", and "...examine the effects of bereavement on...". However, on further examination, only two studies involved any level of direct interaction with PWLD themselves. This seems to contradict the ethos driving such research; that is, the aim to access experiential accounts first hand from the target population.

Across the 10 studies, a wide range of cognitive abilities were represented, from individuals with mild LD to those with profound LD. However the measures used to define cognitive ability varied between studies. In some of the studies it was unclear if the data originated from the individuals with LD themselves, their carers, or the researchers' interpretations of such data. Many of the self-report measures used were of a 'forced-choice' format, thus limiting freedom of expression. One study noted that, despite having intended to interview PWLD themselves, they were not granted ethical approval to do so. The reason for this was not stated, but would have made an interesting addition.

Another feature of the sampled literature was the use of assessment tools and scales originally designed to detect pathological presentations in the general population as measures of grief in PWLD. This is concerning because it assumes the presence of abnormal grieving and may result in the overestimation of pathology in PWLD. It may also be that such measures with pre-determined scales are too prescriptive when assessing the manifestations of grief, given its individualised nature. Other measures used focussed upon levels of challenging behaviour. This may result in over-representation of 'positive' symptoms of grief and neglect of 'negative' symptoms such as withdrawal or low mood.

It is interesting to observe the tendency among researchers to attempt to access the experiences of PWLD via third parties, and the assumption that such experiences can be adequately captured by means of more structured quantitative measures. This raises questions regarding the direct involvement of PWLD in research studies, and the methods used to facilitate such involvement.

1.8 Involvement of PWLD in Research

Before the 1980's most research included PWLD solely as subjects to carry out research 'upon' (Barnes & Mercer, 1997; Chappell, 2000). This pattern fit with the social tendency at the time of exclusion, rather than the promotion of equal rights and inclusion (Walmsley, 2001). A systematic review carried out in 1984 found the existence of only five studies whose participants had LD (Richards, 1984; in Booth & Booth, 1996). However the last few decades have seen a shift in the way PWLD are involved in research. Recent years

have seen them be included in a more active role; that is to say, researched 'with' rather than 'on' (Nind, 2008).

This has been aided by the publication of documents such as the Scottish Executive's review of services in 2000 and the Department of Health's Valuing People White Paper (2001) which set out to improve services for PWLD, promoting their civil rights, independence, choice, and inclusion. This new-found inclusive culture has given rise to the new methodological style termed in the literature as 'participatory' research (Cornwall & Jewkes, 1995).

1.8.1 Participatory Research

Cocks and Cockram (1995) define participatory research as having the following characteristics:

- the research problem may be identified by either disabled or non-disabled researchers, who then bring it to the attention of a constituency of disabled people;
- disabled people and researchers work together to achieve a collective analysis of the research problem; and,
- alliances are formed between disabled people, researchers and other experts, although these alliances must be 'under the control and primarily in the interests' of the disabled people. (Cocks & Cockram, 1995)

The increasing popularity of this approach is demonstrated by the creation of the Learning Disability Research Initiative (Grant & Ramcharan, 2007). This initiative ensures that, before making decisions regarding the funding of research projects related to PWLD, a contingent of PWLD are consulted on

which projects they believe will be the most beneficial to their lives and services. There are now more examples of PWLD being included as active participants, with some funding bodies insisting upon their inclusion as a condition of researchers receiving funding (Kiernan, 1999; Walmsley, 2001; Ward, 1997).

Increasingly researchers have seen the benefit of listening to what PWLD have to say and studies are more often incorporating PWLD as 'experts' in their own field – that of having LD and the impact this has on their lives (Atkinson & Williams, 1990). This results in stronger research findings of better quality and relevance and allows the participants to redress the historical power imbalance where the non-disabled researcher was previously seen as the expert (Stalker, 1998). Instead PWLD have reported the benefits of being involved in research such as feeling helpful and realising they have something valuable to offer (Dye *et al.*, 2004; Ramcharan *et al.*, 2004).

1.9 Methodological Considerations

In the past, limited language skills, lack of self-esteem, and learnt compliance have all been seen as barriers to including PWLD as research participants (Booth & Booth, 1996). It would be naïve then to believe that practising participatory research with PWLD would not require traditional research methods to be modified. The challenge has been how best to access the views of a population that are perhaps more accustomed to isolation and oppression (Booth & Booth, 1996).

1.9.1 Qualitative Methodology

More and more, in using participatory methodologies, researchers have made use of qualitative research techniques in order to truly be able to adopt the viewpoint of the participants (Biggerstaff & Thompson, 2008). While quantitative research still has its role to play in doing justice to this more inclusive culture in LD research, to fully maintain the integrity of an individual's account of their experience, and be immersed in their social cognitions, a qualitative approach is recommended (Bryman, 1988). A qualitative methodology truly allows the integrity of the 'author' to be maintained (Chappel, 2000). What follows is a discussion of the research considerations inherent to carrying out qualitative research with PWLD.

1.9.2 Initial Questions

In the initial stages of deciding upon a research topic, one of the main questions a researcher must answer is whom their research serves (Barton, 1999). What costs are involved in the process? Who benefits from the findings? These questions are even more pertinent when carrying out research with PWLD due to their vulnerability to being 'used' for the benefit of the research process alone. Recent ethics policies have focussed upon finding a middle ground between the extent to which the research is in the participant's best interests, while acknowledging the benefit to public interest (Cave & Nichols, 2007). This has led to the position of asking, not 'if' PWLD can be included, but 'how' they can be, even if the topics are of a sensitive nature such as cancer, death and dying (Tuffrey-Wijne *et al.*, 2008).

1.9.3 Recruitment Considerations

In involving PWLD the researcher must pay close attention to their recruitment criteria and methods. Unfortunately, in past years there has been an almost overly cautious approach to the participation of PWLD (Boote *et al.*, 2002). Many have described the 'hierarchy of gatekeepers' that researchers must navigate in order to access vulnerable groups, starting with the ethical approval needed, then navigating tiers of service management, and finally accessing the PWLD themselves (Hood *et al.*, 1996; Lennox *et al.*, 2005). This protection exists with the best interests of the population in mind. However there is a balance to be struck to ensure that (a) PWLD are not overly cloistered and therefore have their views excluded, and (b) the ethical approval process is not so restrictive as to discourage research proposals and prevent valuable research from being carried out (Iacono & Murray, 2003).

1.9.4 Obtaining Informed Consent

To any good researcher obtaining participant consent is not only a legal requirement but also a moral responsibility. Historically it has been assumed that PWLD are unable to provide consent for themselves (The British Psychological Society, 2006). However this standpoint has changed radically with the introduction in the year 2000 of new legislation in the form of the Adults with Incapacity (Scotland) Act (Scottish Executive, 2000). It provides clear criteria under which an adult can be said to be able or unable to make decisions on their own behalf, thus ensuring that PWLD receive the same rights and freedoms as the general population.

It has been emphasised that in a population where individuals may be accustomed to restricted choices, denied opportunities, and poor decision-making support, extra care has to be taken to ensure that informed consent is truly valid (Harris, 2003). Recommended methods include ensuring that information is in an accessible format, being vigilant for passive acquiescence, frequently checking the reliability of an individual's decision, and being aware of the potential influence of any power dynamics (Brooks & Davies, 2008; Cameron & Murphy, 2007; Freedman, 2001; Harris, 2003).

1.9.5 Data Collection

Interviewing is often a key component of qualitative research. It is through interviews that the researcher can elicit a participant's view and hear their story. Booth and Booth (1996) described some of the barriers to interviewing PWLD; inarticulateness, unresponsiveness, difficulty generalising, difficulty thinking in abstract terms, and difficulties with time-oriented questions. Yet they also stressed that these barriers are not insurmountable with the correct methodology. Of course groups are not naturally homogenous entities and PWLD as a group are no different. Therefore there can be no single 'safe' methodology suitable for all, but rather a range of suggested techniques and adaptations that maximise participant potential (Nind, 2008). Munford *et al.* (2008) refer to these as comprising a 'bag of tools' that a researcher has at his or her disposal.

Establishing an initial rapport with a participant with LD is fundamentally important to the research relationship and this relationship must to be continually monitored so that appropriate boundaries are maintained.

Typically, involvement in research will be a time-limited affair and will not result in a long-term connection of any kind with the researcher. Therefore care must be taken to make the nature of the relationship explicit so as to avoid the creation of an apparent 'friendship' (Rogers, 1999). On the other hand, someone with LD may be reluctant to engage with someone whom they see as 'a professional' assuming that any involvement will lead to some form of professional 'intervention' (Rogers, 1999; Stalker, 1998). Therefore a balance has to be found, with some researchers acknowledging that such boundaries are difficult to maintain and admitting that they had in fact inadvertently become friends with their participants (Atkinson, 1993; Swain *et al.*, 1998).

Allowing participants the option of having a familiar, supportive adult sit in during an interview may make them feel more comfortable. It may also bolster their self-esteem and make them more likely to feel their story is worth telling (Lewis & Porter, 2004; Nind, 2008). There is debate in the literature as to whether a known other should play a larger part; corroborating the participant's account, adding missing information, or even relaying the participant's narrative for them (Atkinson, 1997; Goodley, 1996; Whitehurst, 2007). Their inclusion could affect the aim of a study by diluting the authenticity of the contribution of PWLD. Goodley (1996) suggests that the totality or reliability of a participant's account is irrelevant - there is rich data in the way an experience is recounted, as their own, whether factually accurate or not.

Regarding communication techniques, the literature contains advice on how to maximise a participant's understanding of interview questions. Visual communication aids are suggested for those with difficulties expressing themselves verbally (Bunning & Steel, 2007; Lewis *et al.*, 2008), while attention must also be given to the way in which questions are asked. Generally, open-ended questions are used in qualitative research in order to minimise the presence of leading lines of enquiry, and maintain the authenticity of the narrative (Labuschagne, 2003). However PWLD may have trouble with open questions, depending on their level of ability. They may instead benefit from a more structured interview style, using a more direct style of questioning, without, of course, being so structured as to limit possible responses and conversation flow. (Booth & Booth, 1996). PWLD may have trouble with remembering the sequence of past events and can be aided by the use of a visual timeline that can be used to link stories and feelings with certain events.

A powerful and often dismissed form of communication is that of silence. Too often PWLD who respond with silence are assumed to either not understand, have nothing to say, or not wish to participate. Biklen and Moseley (1988) caution against this assumption and stress that, to the qualitative researcher, nothing – not even silence - should be regarded as insignificant. Neither should the researcher be tempted to try and fill the gaps left by a participant's silence (Stalker, 1998). This could prematurely cut-off a participant's developing response, or otherwise influence the response given.

It is clear then that conducting qualitative research with PWLD can be a complex procedure. However this does not make it impossible. Nind (2008) described it as “challenging but achievable”, an attitude that is more ethically sound than one of exclusion for the sake of ease.

1.9.6 Sensitive Topics

Some suggest that there are certain areas of human life and experience that are simply too delicate and should never be the focus of research of any kind (MacIntyre, 1982). There are many different definitions of what constitutes ‘sensitive’ research within the literature. Most focus upon the potentially negative consequences the research may have upon participants (Dickson-Swift *et al.*, 2008; Renzetti & Lee, 1993; Sieber & Stanley, 1988). It is the role of the researcher, in designing a study, to weigh up the potential risks and benefits that participants may face. Unfortunately this is not an easy task as there is no set formula to make a decision either way. Neither is there a fixed perception of risk across populations but rather a pattern of varying social sensitivity.

There is inherent danger in shying away from researching certain topics for fear of their sensitive nature. It is this kind of reluctance that allows social stereotypes and assumptions to go unchallenged (Lee, 1993). It is only by researching an area and breaking the ‘vicious cycle’ of hesitant unfamiliarity that a greater understanding can be gained and problems addressed (Sieber & Stanley, 1988).

In defending her decision to research one such subject, namely sexuality among women with LD, McCarthy (1998) argued that, so long as steps are

taken to ensure participants are treated respectfully and any potential for exploitation has been avoided, then the measure of whether or not a topic ought to be researched is the participants' willingness to share their personal experiences. Provided the necessary ethical precautions have been taken and informed consent has been obtained then it is an individual's right to be heard.

McCarthy (1998) also points out the tendency for critics to focus upon the negative effects of taking part in sensitive research. This assumes that the experience is upsetting. Conversely, PWLD have reported a desire to talk about even sensitive topics such as death and dying, and have been able to reflect on the benefits of having the opportunity to voice their account (Read *et al.*, 2000; Read & Papakosta-Harvey, 2004). Secondly there is an assumption that it is fundamentally intolerable for participants to be in any way upset. However, having established that PWLD are subject to the same range of normal emotions as the general population, it could be argued that to exclude them on the basis that they may experience such emotions would constitute discrimination. Perhaps wariness of PWLD being seen to express strong emotions is reflective of researcher anxiety rather than PWLD themselves wishing to avoid such expression.

Clearly this makes the obtaining of informed consent a vital procedural component. An individual must be advised of the topic to be discussed beforehand and be able to show some awareness of the possibly upsetting nature of the topic before agreeing to take part. However, even when such procedures are followed it is unclear whether informed consent can ever truly be assumed before an event has taken place or whether it is in fact only

'in the doing' that a true understanding of the implications is reached (Chappell, 2000). It may be that the key lies in researchers remaining flexible as to the shape their research takes; allowing the participants some control over what direction an interview takes; allowing them to include or dismiss certain topics as they see fit; and not entering the research relationship with a pre-set notion of what the data will show. This well describes the spirit in which qualitative research is carried out and the manner in which it seeks to answer a research question.

1.10 Study Aim

Recent years have seen an increased focus on the inclusion of PWLD in society along with a growing awareness of their human rights (Department of Health, 2001). This has seen application in areas such as living arrangements, issues of capacity and consent, and integration into general society (Scottish Executive, Health Department, 2000). However the topic of bereavement and grief in relation to PWLD remains under-researched and relatively misunderstood, with much of the focus remaining upon the beliefs of family member and carers rather than the individuals with LD themselves (Booth & Booth, 1994). Given that there is little in the way of existing research that accesses the bereavement experiences of PWLD directly, the current study aims to explore, by means of direct semi-structured interviews, the lived experience of bereavement and grief for a small group of individuals with mild LD.

It is important to remember that PWLD do not form a homogenous group. In other words, individuals will possess very different cognitive profiles which will affect their ability to articulate their emotional experiences. Therefore the

current study does not attempt to define the experience of bereavement and grief for PWLD as a group, but to provide a forum in which to draw attention to the relevant issues and to provide a sample of reported experiences.

2 METHODOLOGY

The aim of this chapter is to clearly outline the methods used in data collection and analysis, and to provide a rationale for choosing those methods. The techniques used to ensure quality within the current study are also described.

2.1 Study Design

Research on how individuals with LDs experience bereavement and grief has to date focussed mainly upon the manifestations that can be observed and measured by others. This method results in unavoidable subjective biases being present in both the results and their interpretation. The present study aimed to avoid this by acquiring the relevant information first hand. Thus, in line with the principle “Nothing about us without us” (Smyth & Williamson, 2004), it was decided to interview individuals with LD directly, rather than use second-hand information provided by family members or carers.

2.1.1 Qualitative Methodology

A qualitative design was identified as the most appropriate to meet the research aim of exploring the experiences of bereavement and grief in adults with mild LD. A qualitative methodology best facilitated the gathering of rich data required to reflect individual experience (Patton, 1990).

Phenomenological qualitative research is concerned with the exploration of, and inquiry into, various phenomena. It looks to discover how people experience events and what meaning they make of them. Interpretative

phenomenological analysis (IPA) is concerned with investigating how people make sense of major life experiences (Smith & Osborn, 2008). The IPA approach classes each discrete life experience in two ways; firstly as an individual event that encompasses its own detail and interpretation, and secondly, as a part of life that can be interpreted in light of other commonly themed experiences, worthy of separate interpretation as a comprehensive unit. A researcher using the IPA approach in turn takes on a dual role; firstly, hearing the experience as related by the participant's narrative and sharing in the interpretation provided by that individual; and secondly, by employing their own sense-making skills in a systematic way in order to find the over-arching themes encompassed within by exploring convergence and divergence between individual cases. Thus, interpretation moves from an individual to group level.

IPA is concerned with investigation of the 'process' rather than classification of 'outcome'. It aims to capture the essence of what matters most to people by understanding how individuals make sense of their experiences, and in turn, the world around them. Willig (2001) described this as having an interest in the "quality and texture of experience" rather than the identification of cause and effect-style relationships. IPA makes use of third-person enquiry in order to access the first-person perspective and uses systematic analysis to situate personal meaning in the wider context of human experience. Thus, the IPA method allowed the researcher to access individual experiences rather than obtaining a 'typical' picture of grief, as may be obtained through quantitative research.

In summary, given the exploratory nature of the research question and its intrinsic need for subjectivity, qualitative methods were considered to be the most appropriate. IPA was chosen as the most appropriate qualitative methodology as it allows the researcher to listen to and understand individual experiences, and then make further interpretation at a group level, without having to develop an explanatory framework or theory (Starks & Brown-Trinidad, 2007). Other studies have demonstrated that IPA is an effective method of accessing the views of PWLD (Brown & Beail, 2009; Cookson & Dickson, 2010; Isherwood *et al.*, 2007; Longo & Scior, 2004; Mitchell *et al.*, 2006). The current study aims to access the participants' reflections on their experiences of bereavement and grief and to make sense of these experiences in relation to the relevant literature (Smith & Osborn, 2008).

2.2 Ethical Considerations

Every research study will have its own ethical considerations. However in the current study, the process of ensuring sound ethical principles required additional consideration given the potential vulnerability of the sample population (PWLD).

2.2.1 Ethical Approval

Ethical approval for this study was granted by the Programme Organisation Group of the Doctorate in Clinical Psychology at the University of Edinburgh. Advice was also sought from the appropriate National Health Service (NHS) Ethics Committee, who indicated that, because the research was taking place through external organisations, NHS ethical approval was not required (Appendix 2). As the research was being conducted by an

employee of the NHS it was necessary to seek approval from the NHS Research and Development Department, which was duly granted (Appendix 3).

2.2.2 Motivation to Participate / Privacy

In order to avoid participants agreeing to take part out of compliance alone, all initial contact was made via service management, with any further contact established on the participant's own initiative. The participants did not meet the researcher until they had already expressed, through a key worker, their interest in participating. This method also maintained the privacy of possible participants, while allowing the opportunity to participate, should they wish to.

This approach had its disadvantages, such as a lack of control over how the research was initially presented to possible participants, and the potential for the participant to be influenced by their relationship with the informant. However on balance it was judged to be the most ethical approach, avoiding unnecessary breaches of confidentiality, and the influence of the authority that may be attached to the role of a researcher.

2.2.3 Informed Consent

It was understood from the outset of the research that obtaining consent meant more than just having people agree to be interviewed. In line with the recommendations made by the British Psychological Society (2004), all participants were provided with information sheets describing the full implications of being involved in the research (Appendix 4). This

information was provided in the full knowledge that understanding may actually discourage participation (March *et al.*, 1997).

The information sheet was written using simplified language, with the aid of symbols. Possible participants were made aware that the interview subject matter could possibly be upsetting and were clearly told of their ability to leave the study at any time without any adverse effects. Sufficient time was allowed at each meeting to reiterate these points and to answer any questions participants may have. As it has been suggested that true understanding is reached 'in the doing', informed consent was obtained anew for each interview session (Chappell, 2000). All participants were deemed to be able to consent on their own behalf as they did not have a legally appointed Guardian or require an Incapacity Certificate.

2.2.4 The Sensitive Nature of the Research Topic

One potential issue was that of the emotive and possibly distressing nature of the subject matter covered in the interviews. When considering this issue the researcher reflected upon issues such as inclusion and the opportunity to express one's perspective. It was decided that, while it would be reasonable to expect people to become upset when recalling a loss, this should not preclude an individual from expressing their view. Given that all participants had been given a comprehensive description of what participation involved, and that the process of obtaining informed consent had been carefully addressed, it was seen that willingness to participate and share their experience transcended any presumed negative effects (McCarthy, 1998).

While being prepared to provide sympathy and comfort to participants who became upset, care was taken not to give the impression of the provision of a counselling-type service. This was done by explicitly stating from the point of initial contact that participants would meet with the researcher twice at most, and that each session would not exceed an hour in length. The researcher also made the decision before commencing interviews that if, at any time, it became apparent that a participant required therapeutic help, that this would take priority over interviewing. However, this situation was avoided by careful screening during the obtaining of consent.

2.2.5 Confidentiality

Before committing to participation, participants were made aware that the interviews would be digitally recorded. It was made clear that the only person who would hear these recordings would be the researcher. At the point of transcription all identifying data was removed and a pseudonym was allocated to each participant. Following transcription, the original recordings were destroyed.

2.2.6 Dissemination of Results

At the stage of giving consent participants were offered the opportunity to receive a short summary of what was covered in their interview, for the purposes of their own information, or to share with others if desired. This was to be completed several weeks after interview, after transcription and coding was completed. However, none of the participants took up this option.

2.3 Participant Recruitment

The process of recruiting participants will now be outlined.

2.3.1 Sampling

A purposive sampling approach was used in the recruitment of participants. This involves participants being selected on the basis of their expertise in providing information relevant to the research question, rather than their being representative of a wider population (Marshall, 1996).

Power calculations are not carried out in qualitative research. Rather the researcher aims to recruit a sample that is large enough to adequately represent the target population, whilst being small enough to make manageable the required level of in-depth analysis. Although sample sizes vary between studies, Smith & Eatough (2007) recommend a sample size of between six and eight when carrying out postgraduate research. In anticipating that PWLD may not be able to provide the depth or volume of narrative typically required by qualitative methods, it was thought best to recruit a slightly larger number of participants as a means of accounting for any shortage of raw data. The technique of sampling to saturation (discontinuing data collection at the point where the emergence of any new themes seems unlikely) further guided sample size in the current study.

2.3.2 Inclusion / Exclusion Criteria

Table 2 shows the inclusion and exclusion criteria used in participant recruitment. Participants were assessed in relation to these criteria firstly by service managers and keyworkers, and then, if suitable, re-assessed by the researcher pre-inclusion.

Table 2: Inclusion / Exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Aged over 18 years • Mild learning disability as evidenced by historical information/present communication/functional abilities • Ability to give informed consent to participation • Experience of the death of a close relative, friend or staff member within the last 3 years 	<ul style="list-style-type: none"> • Presence of an Autistic Spectrum disorder, due to the possible limiting effects upon communication • Presence of a dementia-type illness, due to the possible limiting effects upon memory/consistency of verbal account • Communication difficulties which prevent clear and consistent expression • Anyone for whom participation would be deemed to be unhelpful (e.g. apparent presence of emotional difficulties)

The inclusion criterion of mild learning disability was used to identify participants who would be most likely to have the necessary communication abilities to take part in the study, and be most likely to be able to understand the research process and therefore provide informed consent. Individuals for whom participation may be unhelpful included anyone whom either care staff or the researcher judged to be too recently bereaved, and/or those who demonstrated a level of emotional distress that warranted concern for their wellbeing and/or state of mind in this regard. In making these judgements, care staff made use of their established knowledge of, and familiarity with, the possible participant, while the researcher relied upon her clinical judgement and expertise in working with PWLD and individuals with mental health problems.

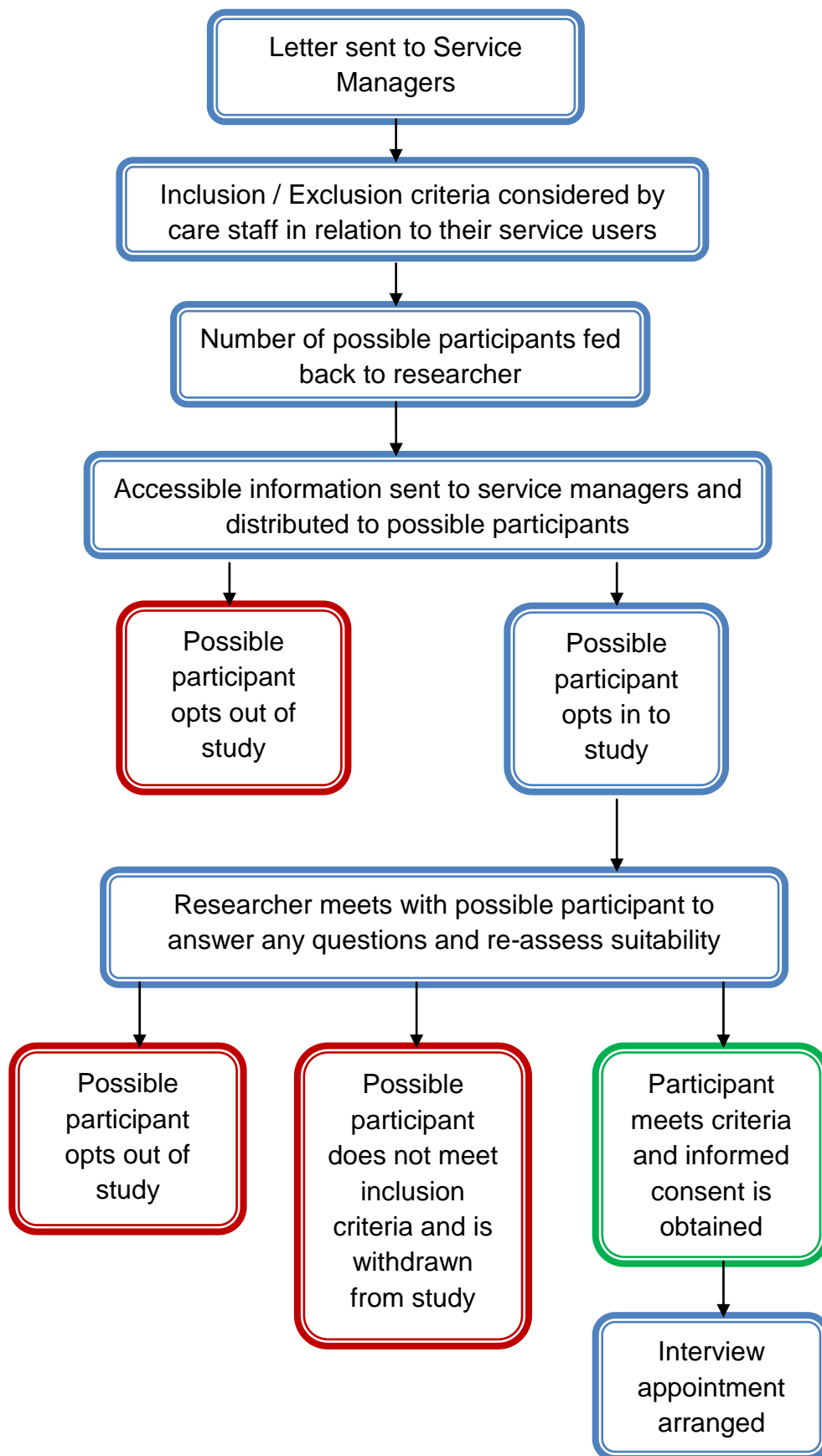
2.3.3 Participant Identification and Contact

Participants were recruited through day service providers in the local area. These were identified using information within the public domain. Contact was initially made with service managers in the form of a letter (see Appendix 5) detailing the purpose of the research and its inclusion/exclusion criteria, and requesting their assistance in facilitating contact with their service users. Service managers/keyworkers were encouraged, if required, to contact the researcher for further explanation at this point. Service managers/keyworkers were asked to identify possible participants using the inclusion and exclusion criteria provided, and contact the researcher with an estimation of possible participant numbers. This allowed for carers' views on individuals' capacity to be incorporated, making use of their established knowledge of the individual (Nind, 2008; Walmsley, 2004).

An invitation letter (see Appendix 6) was then sent to each identified individual. These letters were written using simplified language with the aid of symbols. Individuals were asked to contact the researcher independently or via their key worker if they were interested in discussing participation further. At this point several identified persons declined to take part in the study, thus providing reassurance that the recruitment method was sufficiently sensitive to permit informed choice.

Once initial contact with possible participants was made, a pre-interview appointment was arranged through which the researcher could answer any questions possible participants may have, gauge the person's ability to participate and, if deemed suitable, obtain informed consent. This also provided a second opportunity for possible participants to be considered in relation to the study's inclusion and exclusion criteria, this time making use of the researcher's clinical judgement and expertise. Any participants deemed not to meet inclusion criteria were excluded. For those deemed suitable, informed consent was obtained and an appointment was made to carry out the research interview. The entire recruitment process is depicted in Figure 1.

Figure 1: Flowchart of recruitment process



Approximately two days before interview participants received a reminder letter of their appointment and were encouraged to bring along photographs or mementos of the deceased, should they wish to.

2.4 Participant Characteristics

Initially, 23 individuals were identified by care staff as possible participants. Several of these individuals did not go on to participate in the study (see Figure 2). Six possible participants opted out of the study at the initial introduction of information stage. A further four possible participants were deemed upon assessment by the researcher not to meet the study's inclusion criteria. Therefore, the final sample consisted of thirteen participants.

Participants consisted of 8 males and 5 females. They were aged between 20 and 72 years. Table 3 provides a brief description of each participant and their circumstances:

Figure 2: Number of participants identified, excluded and recruited

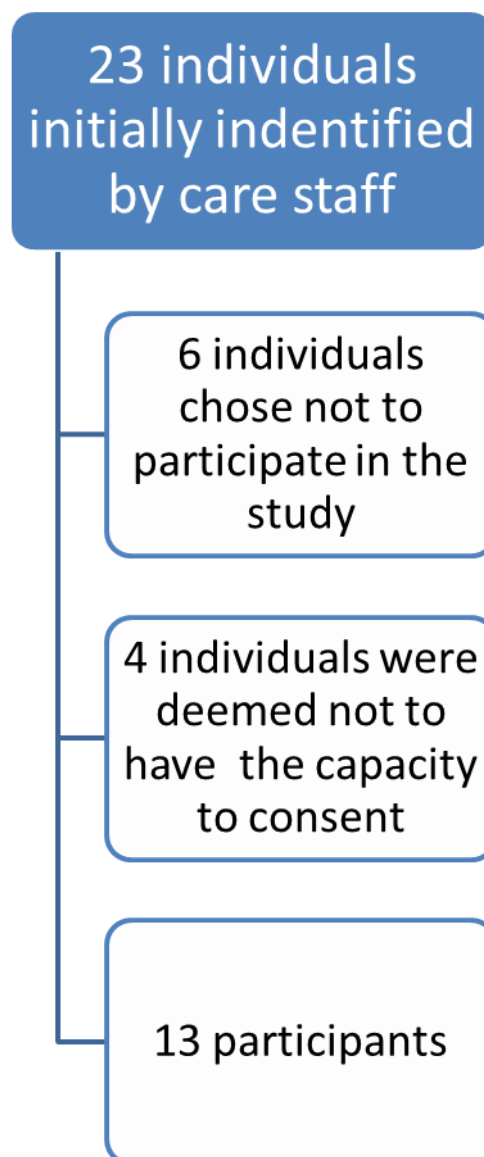


Table 3: Participant Characteristics

Name⁴	Age	Bereavement⁵	Home	Day Service
Alan	26	Parents	Shared tenancy	Sheltered employment
Beth	39	Friend	Group home	Day centre
Bill	32	Friend	Own tenancy	Sheltered employment
Jack	44	Parents	Group home	Day centre
Jane	58	Mother	Group home	Sheltered employment
Jeremy	37	Parents	Group home	Day centre
Katie	42	Parents	Group home	Day centre
Keith	70	Flatmate	Shared tenancy	Sheltered employment
Kevin	52	Parents	Own tenancy	Sheltered employment
Louise	28	Father	Group home	Day centre
Mary	72	Partner	Nursing home	None
Matthew	33	Mother	Group home	Day centre
Norman	20	Grandparents	Group home	Sheltered employment

⁴ Pseudonym allocated at the point of transcription.

⁵ While this was the participants' most recent bereavement, they may have also discussed past bereavements during the course of their interviews.

2.5 Data Collection

Research interviews were carried out at a location of the participant's choice, whether at his or her home or day service. Five participants chose to be interviewed at home, while 7 chose to be interviewed at their day service. Participants were given the option of having a member of known staff, such as their key worker, sit in on the interview. Two participants chose to have someone sit in, in both cases, their key worker.

Before the interview commenced, participants' capacity to give informed consent was again assessed, using focussed questions on what participation involved and the implications of participation (Appendix 7). All participants were deemed to have maintained their understanding of participation and to have made an informed decision to consent. Participants then completed and signed a declaration of consent (Appendix 8), and the interview commenced.

All interviews were carried out by the researcher. A semi-structured interview format was chosen. This fitted well with the study aim to provide a flexible forum in which participants could relate their experience; something that would have been prevented by the use of a more structured, questionnaire-like format (Lewis, 2004). It allowed the interview to better follow the interests and concerns of the individual, while allowing the researcher to further probe areas of interest (Smith, 2008). Studies have shown that individuals with LD can benefit from some level of structure when being interviewed (Booth & Booth, 1996; Gilbert, 2004; Rogers, 1999), and therefore a brief list of questions was used in the form of an interview schedule (See Appendix 9). This served as a guide to interview content and

as an aide-memoir for the researcher. The interview schedule was used solely as a prompt to guide the course of an interview if required.

All participants were initially asked the question “Can you tell me about when X died?” This allowed participants to have control over the direction of the interview. Questions from the interview schedule were used only when participants required prompting. Care was taken to allow periods of silence should the participants require it. The interview schedule was used in pilot form for the first interview with scope for changes should they be required. However the schedule proved to be fit for purpose and so data from the pilot interview was included in the data set.

Participants chose the time of their interview appointment in order to avoid unnecessary disruption to their routine (e.g. activities and mealtimes) and to maximise their ability to participate (e.g. maximise concentration and minimise fatigue). Interviews were carried out in pre-arranged private locations, free from distractions and interruptions. Tissues were provided for use by the participants should they require them. Care was taken to ensure that participants were comfortable with the timing and location of the interview before commencing. Interviews were, with permission, recorded using a digital voice recorder (Olympus WS-400S). This device was small and unobtrusive, and was placed in an inconspicuous location in order to encourage freeness of speech.

2.6 Data Management

Once completed, each interview recording was transferred from the digital recorder onto a password protected data stick. All the interviews were

transcribed by the researcher on the day of recording, using transcription software *Express Scribe*. During transcription, pseudonyms were used and all identifying data was removed. Once transcription was complete the original recordings including identifiable data were deleted from both the digital recorder and the data stick.

2.7 Data Analysis

Interviews varied in duration between approximately 11 and 61 minutes, with a mean interview duration of approximately 33 minutes (n=13). All interviews were transcribed verbatim by the researcher.

Interview data was organised using the *Nvivo9* software package for qualitative data management. Analysis involved the reading and re-reading of each transcript several times in order to be familiar with the data, while noting any points that were thought to be particularly interesting or significant. These initial notes served as the 'left-hand column' aspect of traditional IPA methodology (e.g. Smith & Eatough, 2007), and were used later to help inform the transcript coding process (See Appendix 10 for a sample coded interview).

2.7.1 Transcript Coding

Much like the 'right-hand column' aspect of traditional IPA methodology (e.g. Smith & Eatough, 2007) the *NVivo9* software package was used to code transcripts according to units of meaning identified by the researcher (See Appendix 10 for a sample coded interview). These units of meaning were then identified as emergent themes which in turn represented the data at a more abstract level. The emergent themes were then considered as a whole

and organised into interconnected hierarchies. Each theme maintained memos of the researcher's reasoning for their identification as being significant. In line with IPA procedure, each interview was analysed individually, before comparative analysis was carried out between interviews (See Appendix 11). This allowed for the production of an overall group analysis, while still maintaining the value and importance of each individual participant's experience.

2.7.2 Quality Measures

The concepts of reliability and validity so often used to measure the quality of a quantitative study are not easily equated with a qualitative approach. In fact there is much debate as to whether these concepts apply at all to qualitative research (Golafshani, 2003). Reliability refers to the likelihood of data being dependable and consistent (Clonts, 1992; Lincoln & Guba, 1985; Seale, 1999). However the focus of qualitative research is not to produce generalisable 'trends' as may be the focus in quantitative research. Therefore, scope for replication of results in qualitative research is irrelevant given the focus upon individual experiences and so it can be argued that so long as a study achieves validity, that in itself proves the data to be reliable (Patton, 2002).

The concept of validity is equally as problematic to define in qualitative research. In quantitative research validity typically refers to methodological rigour and how well the findings reflect the concept being measured. In qualitative research it refers to the need to impose some form of 'quality control' criteria upon research studies in order to establish trustworthiness and confidence in the findings (Lincoln & Guba, 1985; Mishler, 2000).

Yardley (2008) proposed four criteria with which researchers could assess quality in qualitative research:

1. sensitivity to context;
2. commitment and rigour;
3. transparency and coherence; and
4. impact and importance.

These criteria will now be discussed in turn with regard to how they were controlled for within the current study.

2.7.2.1 Sensitivity to Context

Sensitivity to the theoretical and socio-cultural context of research is important in qualitative methodologies. This refers to the researcher demonstrating awareness of existing theoretical and empirical literature, and their having paid attention to the power dynamics within the research relationship and how it may impact the study's findings. In the present study, a comprehensive exploration of the relevant literature was carried out at the earliest stages of the research process and this informed the development of the study aims and methodology. Regarding the research relationship, the researcher was constantly mindful of the possible impact her role as a Trainee Clinical Psychologist could have upon participants. For this reason, none of the participants were individuals with whom there had been any previous clinical contact, and it was made clear from the outset the extent of participant involvement with the researcher. The chosen methodology made sure of participants' ability to decline involvement, and those who did participate were told that their responses would be anonymised.

2.7.2.2 Commitment and Rigour

Commitment refers to the researcher becoming fully engaged with the research topic and demonstrating a rationale for the methods used, the data collected, and the findings evidenced. This is evidenced in the current study by the level of attention paid to each participant, both during interview, and at the stage of analysing transcripts. The many stages involved in analysing the data allowed the researcher to become fully immersed in the individual accounts and thus the topic in general.

Rigour refers to the extent to which the researcher has demonstrated an in-depth analysis of the data and quality-control measures such as sampling, triangulation and respondent validation checks. Purposive sampling was utilised in order to keep the sample as relevant and homogenous as possible. Each participant was individually assessed as to their suitability to participate in the research. Triangulation of data was used to compare and refine interpretation of individual participant accounts. Sample interview transcripts were reviewed by both a clinical supervisor with experience of working with PWLD, and an academic supervisor with experience in carrying out qualitative research. This allowed for second and third opinions on the appropriateness of data collection and data analysis, while creating the opportunity for refining interpretative methods.

Checking for consistency in interviews can be helped by corroborating information provided with external individuals. This can be achieved via family members, carers, or by checking written records. However, this could be said to undermine the essence of a qualitative approach. External sources cannot shed any light upon an individual's feelings or perceptions, and thus cannot truly reflect upon their experience of events. Rather, the researcher is

best served to adopt the approach of remaining impartial to the factual nature of an account, accepting their narrative as their experience of the event – whether it is the truth or not is irrelevant, their experience is what matters (Goodley, 1996).

Due to both time constraints and the potential vulnerability of the sample population it was deemed inappropriate to carry out respondent validation checks in the standard, follow-up manner. This is unfortunate as it removes an opportunity for the individuals with LD to maintain ownership of their account (Willig, 2001). However the researcher desired to avoid participants having multiple contacts with her in the interests of maintaining appropriate relationship boundaries. Also it was hypothesised that, should the researcher return to validate participant accounts with them at a later date, participants may interpret this as having given inadequate or inaccurate information at the point of first contact. In order to avoid unnecessary distress therefore, time was taken at the end of each interview to summarise the content of the interview and to check the researcher's understanding of the account matched with that of the participant. Also, once data analysis began, the emergence of common themes both within and between participant accounts provided confirmation of patterns in experience, thus validating individual accounts.

2.7.2.3 Transparency and Coherence

Transparency refers to the clear, unambiguous documentation of all stages of the research process, while coherence refers to the 'goodness of fit' between the theoretical bases for the study and the methods used. Methods and interpretations should be recorded clearly so that, if desired, the study could

be replicated to the same standard. In the current study the write-up contains a step-by-step account of the methods used and the rationale for using such methods. Interpretation of the data is clearly explained and interview samples are provided to back up these interpretations. The researcher has also made clear, by the inclusion of a 'Reflections' chapter (See chapter 4), any influences, internal or external, which may have affected either the collection or interpretation of data at any stage of the research process.

2.7.2.4 Impact and Importance

The final principles of impact and importance refer to the extent to which a research study contributes to existing theoretical knowledge, and through its findings, provides suitable recommendations for clinical practice. The initial process of becoming familiar with the existing literature showed a strong argument for research of this kind. There exist multiple studies regarding how best to manage the emotional and behavioural responses of PWLD following bereavement, along with a vast array of suggested interventions and therapeutic groups (Cathcart, 1995; Dowling *et al.*, 2006; Elliott, 1995; Persaud & Persaud, 1997; Summers & Witts, 2003). Therefore there exists a clear need for a research study that aims to gather first-hand accounts of the lived experience of PWLD in relation to bereavement and grief.

3 RESULTS

The aim of this chapter is to present the main findings from the analysis of the interview transcripts, within the context of the original research question; that is, how adults with mild LD experience bereavement and grief.

3.1 Main Themes

The analysis of the interview transcripts at group level resulted in the discovery of four main themes. It was interpreted that each individual's bereavement and grief experience became individualised subject to the level to which each participant experienced and placed value upon each theme. The four themes are

- inter- and intra-personal experiences;
- core beliefs about life and death;
- level of inclusion; and
- continuing relationship with the deceased.

The first theme of 'inter- and intra-personal experiences' incorporated a participant's description of their experience of bereavement and grief both from the standpoint of their own inner experiences, and those between themselves and others. The second theme of 'core beliefs about life and death' reflected a participant's internal model of the world and how it relates to the phenomena of life and death. The third theme of 'level of inclusion' encompassed the level to which each participant was included in the entire bereavement process. The fourth theme of 'continuing relationship with the

deceased' provided insight into how and to what extent participants went on to incorporate their relationship with the deceased into their on-going life.

Each theme will now be presented in turn, comprising a description of the related sub-themes, evidenced by salient quotes from interview transcripts.

3.1.1 Intra- and Inter-personal Experiences

The theme of intra- and inter-personal experiences included several experiential features of each participant's 'journey'; from being notified of their loved one's illness or death, the accompanying emotional experiences, through events such as the funeral, and then on to the later after-effects. These aspects were highlighted by participants as important aspects of their lived experience. The sub-themes can be further divided as intra- or inter-personal. The sub-themes interpreted as intra-personal experiences are emotional response, losses, and helplessness. The sub-themes interpreted as Inter-personal experiences are exclusion, support, and changes in roles and responsibilities. Interestingly, although the data showed variance in the number of sub-themes invested in by participants, all participant accounts reflected an appreciation of both intra- and inter-personal experiences, with no participant ascribing solely to one type or the other.

3.1.1.1 Emotional Response

When exploring someone's bereavement experience, perhaps the first question that comes to mind is how it felt, emotionally and physically. Participants described experiencing a wide range of feelings during their initial grief, including sadness, worry, being upset, crying, loneliness, denial, helplessness and avoidance.

Well first when I hear that a person has passed away you can't believe what you've been told. (Alan)

Didn't feel like coming out... Tired. And I feel a bit lost... I just feel I'm in a corner, left out... Just sad. (Beth)

It's like a time-bomb going off... When you get that phone call it's like sitting in a dark room. Like sitting in a dark room with nobody else in it. You don't know what way to turn. (Bill)

When I got told he'd died, I obviously cried, but it didn't really feel like I was there. It felt like I was kind of like in space. And I didn't think it really happened... Sad. (Louise)

It was a strange feeling... It was just....shaking... I just was wondering if she would come back. But she didn't. (Mary)

One participant (Norman) recalled reacting to being informed of his loss by displaying what would be termed clinically as challenging behaviour, after hearing that the funeral had already taken place and that he had missed the opportunity to attend.

I got a little bit upset because I was at school. So I pulled my personal alarm and I smashed some plates and...I got mental. I hit people. I hit staff... Because it was making me upset. And they had to put me down on the ground. I fought them. Staff tried to put me down... I got up again. Slapped the staff as well... I just got a bit upset. But I can't help that... I HAD to go! Because it's MY granddad [begins to cry]. (Norman)

This participant was able to attribute his behaviour to having been denied an opportunity he felt entitled to experience based upon the relationship he had held with the deceased. Also, despite a considerable amount of time having passed since the event it still held the emotional impact, causing him to become upset when recalling the incident.

The experience of oscillating between different emotional states emerged frequently across participants. Participants were most likely to describe such changeable emotions when recounting the later stages of their grief.

Awful... It feels funny... It goes away... it comes and goes away. (Jeremy)

I was a bit happy but a bit sad. (Matthew)

Sometimes it's happy... and sometimes it's sad. Just depends, what, at the time, I'm thinking of. (Jack)

Sometimes you just get run down and what not. And feel worse. (Katie)

Some participants described feelings that suggested they had not yet fully processed the fact that their loved one was gone, and the permanence of the situation.

Next Wednesday it will be a year and it still seems strange to this day not seeing him walk through that door. (Bill)

On the weekends when I go back to my gran's I look at the chair and my granda's not there. Like sometimes because I live on my own – I've got a bad habit of forgetting that there's nobody there! It's like I think there is somebody else there but there isn't. (Alan)

I even think now he's still alive... I just think I still even now don't think it's real. I just think...I don't know. (Louise)

On the other hand many described a sense of healing over time, and a reduction in the negative emotions they felt during the initial stages of the bereavement.

Sometimes I feel it within me for a while and then it comes alright again. (Jack)

It made me worry to start with. But I fell away from that after a while... I'm kind of used to it now... I never worry about it now. No. (Kevin)

Once I got over it, it wasn't so bad. (Katie)

Such accounts were consistently worded in the past tense. This may suggest the value of time and hindsight in the grieving process. On the other hand, the apparent healing over time may simply be a reflection of the lack of emotional vocabulary held by participants in that their descriptions were fairly basic and came across as either 'happy' or 'sad', with little elaboration in between.

3.1.1.2 Losses

Participants described a wide range of losses that came about as a result of their bereavement. This included the most immediate social loss of the actual person and the role they played such as carer, companion, housemate, or confidante. Participants also described material losses such as the loss of their home, community, and job.

I had to move out. I was told "Just move out right away." Because the Council said I had to be out by a certain time. I wasn't getting to stay there so I had to find somewhere. (Jack)

Then when mother died my sister wanted to live in another house so she moved in by herself. But she only had one bedroom you see, so I moved into my flat... You see it was my two uncles that had the farm and they died too, as well. So they rented the farm out and I didn't have a job [any more]. (Kevin)

My mum used to help me a lot because of me being disabled... I used to stay with her... I was on my own in the beginning but then I got to saying "I can't be bothered doing this, I can't be bothered doing that"... I think I was kind of lonely a bit because the house was empty. (Katie)

Yeah other people listen. But not the same as mum. (Jane)

We have somebody lined up [to fill the deceased's tenancy] – I don't know who it is. We've got one of the residents coming down from upstairs to move into the flat. (Keith)

An example of a less obvious reported loss included the loss of a respite placement that the participant (Matthew) enjoyed attending while their loved one was ill and unable to care for them. One participant (Kevin) described the loss of a parental 'boundary-setting' figure to ensure he behaved himself, while another (Louise) described having lost the person who understood her disability the best. Regarding long-term effects one

participant (Mary) described having lost the comfortingly predictable future she had envisaged for herself and her partner now that he had died.

Participants also showed an awareness of more complex losses. For example, one participant (Jeremy) described how, over time, staff at his day centre who had known his mother while she was alive and therefore could share in his reminiscence had moved on to other jobs, thus leaving him without the opportunity to share his memories to the same degree. Another participant (Jack) showed his awareness of the type of losses that others experience as a result of bereavement. He described how his mother who had died had never had the opportunity to see him settled in his own tenancy and missed out on the joy and pride this would have brought her.

These examples show a high level of insight on behalf of the participants in considering the knock-on effects of bereavement in terms of personal loss, the losses of others, and the changes in their environment. They also demonstrate participants' ability to consider the effects upon individuals other than themselves, providing evidence of empathy as opposed to ego-centrism.

3.1.1.3 Helplessness

One experience that came up time and again across participants was the feeling of helplessness. The first way in which this manifested itself was as a feeling of powerless; being unable to make their loved one better and unable to prevent losing them to death.

I've only got 2 grandparents left and then that's it! (Alan)

Oh, but she was old and there's nothing I could do about it. (Kevin)

[There was] the service and then they carried her out. And that was it!
(Mary)

Secondly, helplessness was described in terms of an actual powerlessness; being denied the opportunity to have their individual preferences respected and not having the power to do anything about it.

No I didn't go [to the funeral]. I wish I had. (Beth)

I wish I could have seen her [body]... He [Dad] says he's going to keep it [Mum's ashes] until, if he dies... I just don't feel it's the right thing to do.
(Jane)

It's up to the staff at [day centre] what they do with me... probably they decided what to do [with Mum's ashes]. (Jeremy)

I'll have to stay at home [on the anniversary of gran's death, rather than be with family]. (Norman)

Both scenarios reflected PWLD being in a position of having a less influential social status, and their needs being secondary to those of others. It is difficult to say whether this sense of helplessness would have been a novel experience for participants, or the extent to which they had experienced it in other aspects of their lives and so were acclimatised to such scenarios.

3.1.1.4 Exclusion

Further to the idea of being powerless to assert one's wishes, many participants described being excluded from certain aspects of the bereavement, despite wanting to be involved. This ranged from viewing the body of their loved one, to attending the funeral, and continuing to visit the site of their loved one's remains.

They wouldn't let me... The hospital. I said I wanted to see her body but they wouldn't let me. (Jane)

I wish they had [asked if I wanted to go to the funeral] ... I haven't seen it yet. I would like to see it. Her name. On the stone. (Beth)

I don't know [where the grave is]. They didn't tell me. That's why I don't know... No one takes me. I don't know where she is because no one told me.
(Jeremy)

I did try to say to mum that day she came over and told me – to let me go home with them but they wouldn't let me... Because they had too much to do.
(Louise)

Well if I knew where his ashes were scattered then I would go to see where they were. (Mary)

My mum never – she phoned me and told me that my grandad died and that my family had been to the funeral but not me. I was at school... I HAD to go! Because it's MY grandad! (Norman)

Many of these accounts highlighted situations in which important information had not been communicated effectively to participants. It could be hypothesised that participants had been informed appropriately and had simply forgotten the information. However, invariably, when talking with non-family carers who would be in a position to act upon such information, the researcher found that they too were unapprised of such information.

3.1.1.5 Support

Participants were very clear on how useful they found it to be supported by others in what was their time of need. One participant (Alan) expressed nicely the indispensable role that support from others plays – when asked what he thinks is helpful after experiencing a bereavement, he replied “*Well, as well as being there for each other you mean?*”. Other participants described the relief that sharing their grief with others provided them.

If you share it with somebody it makes it a whole lot lighter than trying to deal with it yourself. (Bill)

I thought I couldn't do it [view the body] but by good fortune my mum and dad and sister were all there with me. Because it takes the thing off a bit if you do it together... I was lucky because I didn't go on my own because I get support staff. (Alan)

Between my sister and all them – they've said to me, they've just helped me come round... I can go to staff. They just speak to you. Ask you how you are. Tell you that they're still with you and... just things that they speak about. (Jack)

Just let people support you. Like if carers, or the centre, or anyone. Let anyone support you. (Louise)

Participants also highlighted that there are times when this type of support is not available, usually due to time pressures.

I haven't had the chance... Just carers been busy. (Beth)

But they DO have five other people to look after in our house... Maybe because I'm too much hard work... just because of my [wheel]chair and stuff... and my condition. (Louise)

One participant (Jack) was clear about the sort of well-meant support that he actually found to be unhelpful.

Some people try and help you. Some just, more or less, just leave you... when they don't bother speaking to you and things like that... and just tell you "Come on. Come on, you'll be alright."... [That makes me] just more a bit sad. (Jack)

Providing another perspective, one participant (Katie) described how being around others who were also grieving was something she found unhelpful.

Well I used to go to [club] too, with my friend. But then she was not very great either so I stopped it. I was getting fed up and it was me that stopped that. I

found it too much for me... My friend was always down in the dumps. I mean she was a good friend but I was trying to think positive. (Katie)

In evaluating their experiences of support, participants demonstrated the ability to reflect upon their experiences and recognise them as helpful or otherwise. It is unknown whether such deductions would influence their ability to request helpful support in future situations.

3.1.1.6 Changes in Roles and Responsibilities

Along with the losses experienced by participants came a seemingly unavoidable change in their roles and the roles of those around them, and an unfailing increase in their level of responsibility. Whether it be taking over more of their own day to day care, or taking on the care of others, many participants experienced a shift in their social dynamic.

She was in the hospital and because, normally on the days I would come here I just said to myself right I can't - I just couldn't concentrate on my work so I said what I'll do is go up and see her. So I went in as much as I could to see her. (Alan)

We had to help her. We had to get a special toilet over there. Because she couldn't walk. (Jane)

She was getting up in the middle of the night – well she had fallen again! In the living room. She would get me up in the middle of the night as well... When she was in hospital and that I went in to see her at the hospital... I nearly went to see her nearly every Sunday. (Katie)

When mum was ill in bed I had to do all the washing because I was the oldest. (Mary)

Participants also observed the way in which the bereavement changed those around them. Several participants were able to rationalise someone's atypical behaviour as being due to their on-going grief, reasoning for example that *"It had been a shock to them maybe"* (Beth). This was most obvious in the case of one participant (Jane) who, when her mother died, witnessed a big change in her father as he struggled with his loss.

He has taken it very badly... He keeps on thinking he wants to die also to be with her... I tell him "YOU ARE NOT DYING!"... I organised the, erm, funeral... Dad didn't want anything to do with it... I got someone to come and help me. Because dad wouldn't do it... And he wants me to go home every weekend. And I keep on saying no. Because this is my home and that's his home. (Jane)

This example shows a reversal in roles where the previously responsible father is now, due to his grief, in need of care and support himself, which he

seeks from his less able daughter. This contradicts the aforementioned idea about how the ability to see that the world continues to function in a similar manner after bereavement may provide a sense of comfort to the bereaved. Instead, the losses described by some participants showed the extent to which the systems in which they existed had changed irreparably.

3.1.2 Core Beliefs About Life and Death

This theme contains information about how an individual views life as a cycle, and death as a natural part of that cycle. The data provided five sub-themes: predictability, causes of death, fairness of death, life goes on, and afterlife beliefs.

Each sub-theme will now be presented along with exemplar quotes from participant interviews.

3.1.2.1 Predictability

In describing the circumstances leading up to their loved one's death, participants revealed how, at various points in the pre-bereavement process, their expectations shifted dependent upon the information made available to them, and the way in which they interpreted that information. Participants made these judgements based upon prior held beliefs, past experiences, and through the incorporation of newly acquired information and/or experiences. They demonstrated the ability to compare states of health and ill-health, and to compare previous bereavement experiences with events most recently witnessed.

For example, many of the participants communicated a sense of the loss having been expected or not. Many described being unaware of any underlying health problems and described the death as unexpected.

I got a bit of a shock. (Kevin)

It was very sudden and totally unexpected. Not expected.⁶ (Louise)

He fell asleep one night and he didn't wake up. Nobody knew...⁷ I actually thought someone was taking the mickey when they turned round and said that he had died in his sleep. (Bill)

Others were aware of their loved one's ill-health but did not realise the potential for this to be life-threatening.

I didn't know what it was although I knew that M⁸ hadn't been very well but didn't realise it was as bad as what it was. (Alan)

I thought she might have got better,⁹ but no. (Jane)

I knew he was bothered with his asthma. But it didn't know that he was in his last days... I just didn't know that it was going to happen so suddenly. (Mary)

⁶ All transcripts were transcribed as spoken by the participants. Therefore any grammatical errors in the examples used are a reflection of the original dialogue.

⁷ Ellipses are used to represent either a prolonged pause or a portion of missing text.

⁸ Initials are used in place of names mentioned by participants.

⁹ Commas are used to represent a short pause in speech.

One the other hand, some participants knew of specific diagnoses and had a sense of impending death.

It was just when she found out she couldn't get another voicebox that was more or less it. And they did as much tests as they could up at the hospital and then... it was... it really hit me. (Alan)

Well I thought she would die quicker. I said to my sister "I can see it". But then she fought to the very end. (Katie)

Well he got frostbite during the war. He had black toes and he got his toes cut off. So... the complications of that. (Keith)

Several participants described being 'fore-warned' of the impending death, either by the loved one themselves, or by others.

And they [care staff]¹⁰ were telling me that "Your mother maybe won't live long now because she's an old lady" you see. (Kevin)

She kept on saying I want to die...so that's what she did. (Jane)

You know the night before he went away and left me he told me this would be his last. That's what he always told me. When we were sitting through there.

¹⁰ [] denotes text added during transcription to aid the reader's understanding.

When he said goodnight. He would always say that that would be the last time I'd see him. (Mary)

Thus, individual experiences differed in the early stages before bereavement depending on the level of information participants held. This demonstrates the role that open communication (or otherwise) plays in how one experiences being notified of a loved one's death.

It can be hypothesised that this initial cognizance and its accompanying emotions may 'set the scene' for how one understands and experiences both the subsequent grief and bereavement process but also future bereavements. There may also be an influence upon how one goes on to exist in subsequent relationships. For example, if an individual has past experience of relationships coming to an unexpected and unforeseen end, one may in the future find it difficult to view remaining attachments as stable, enduring entities.

3.1.2.2 Causes of Death

Through the narration of their bereavement experience many participants shed light upon the relationship they formed between acquired information, and where they attributed blame as far as cause of death. Their attributions tended to be physiological in nature, mainly based upon observable symptoms of illness, and the knock-on effects upon their loved one's ability to carry out daily living skills.

Participants' awareness of the cause of death varied. Some were able to provide specific medically-sound explanations for their loved one's death while others had a less clear picture.

She had cancer... It was cancer she had in her legs and arms. (Jeremy)

She had, eh, was getting breathless and she had actually lots of...what do you call it...like cancer, you know like a stone. Just up the top there [points to neck]. And they had to give her treatment and everything. And she was getting breathless and they had to put her on a machine to do something – that yellow machine with stuff in it to help her. (Jack)

She died because she had stones in her chest... erm... stones in her TUMMY.¹¹ It didn't work... She had stones that didn't work. Her stones. They didn't work. The stones in her chest didn't work. (Matthew)

She was in intensive care and they did do as much as they could for her but before the end her voice box was...they couldn't give her a new voicebox. So they opened her neck and the water was coming out of her neck and then she just, that was her voicebox finished. She couldn't speak. (Alan)

Given the variation in the quality of descriptions it can be hypothesised that participants gleaned their information from various sources. Accounts may reflect information given directly, whether accurate, adapted or otherwise; information pieced together from indirect, overheard accounts; or a

¹¹ Capitalization represents emphasis in speech.

participant's own theory as to their loved one's cause of death, based upon information received or fictional.

3.1.2.3 Fairness of Death

In many cases it was the participant's understanding of the manner of death that influenced their opinion of whether a death was fair and a natural part of life, or unfair and untimely. Variables impacting this opinion included the deceased's wealth of life experience, age at point of death, and level of suffering while still alive.

She was a good age. (Jack)

She never had much trouble... If she'd been younger and had something wrong with her, we would have been more worried about her, maybe. But we just knew she was getting old... She didn't die when she was young you see, just when she was too old. (Kevin)

Well at the end of the day she's not in any more pain any more. She's not suffering with everything that she's got. (Bill)

We all stood there [at the funeral] and we knew that it wasn't his time. That it was just the way it happened... Because he was only 22. He really was young. (Bill)

Therefore, the data suggests that contextual information surrounding a death plays a large part in how the death is accepted by the individual, dependant

on whether or not it was expected, justified and/or fair. For example, the accidental death of a young person was viewed very differently from that of an elderly person who had suffered a long terminal illness. This suggests a wider awareness of the 'laws of nature' and a sense of being entitled to a life that adheres to these laws.

3.1.2.4 Afterlife Beliefs

The way in which participants made sense of a bereavement was also affected by the beliefs they held (religious or otherwise) about what happened to their loved one after death.

Eleven of the thirteen participants talked about where they believed their loved one to be now, and whether or not this belief was helpful in dealing with their grief or not. Many of the beliefs revolved around the existence of a 'heaven' and captured the sense of someone being at peace or at rest.

She must be in heaven... Up in space. (Beth)

They're not actually in that body anymore... Well they're sitting in between, aren't they. I'm a firm believer that there is guardian angels out there somewhere, but they're sort of sitting in between until you've done the funeral. Then they either go down or otherwise they go up... You know he's at rest because he's back to where he'd like to be. (Bill)

I'll see mum again when I'm dead. (Jane)

Well, she's still in the graveyard. She's along with her man you see. They're both together you see. (Kevin)

I also think not just dad, but any dead person, are probably in the wind on a day like this. In the wind, in the air. And I just think they're just floating about in the wind. Like invisible – we can't see them, but they're floating. I don't mean just dad, I mean every dead person. They're floating about in the wind. (Louise)

In addition to, and perhaps because of these beliefs, many of the participants felt that they still had a connection of some kind with their loved one, albeit unidirectional communication. Only one participant described feeling an on-going ability to communicate with the deceased.

I just see that when they're buried in the ground they are just up in heaven and they're just watching over you. You know? Like more or less every day. (Alan)

I believe that, well, they are watching you and they're still with you. Because I get told at church, well they say that a part of their body is still with you. Do you know what I mean?... You just stand there [at the graveside] and it's like them speaking to you... It's just, well you think about them and that they're there. And, as folk say, they can see what you're doing and everything. (Jack)

I think he's kind of upstairs looking over on us... I still think he's around.

(Louise)

She's still looking. (Matthew)

She's still in my heart. She speaks to me in my sleep... She tells me to calm down and not get a bit upset and whispers in my ear. She whispers in my ear and says "How's my family doing?" I just tell her about something between me and her, and that's that. (Norman)

When those who expressed a belief in their loved one looking down on them were asked how this made them feel, the answer was unanimously positive.

I actually look at it as a good thing because they want to know what's happening, what you're up to, what's going on. (Alan)

It makes me feel a little bit better. Because they're there and they know what's...well, IF it's true that they're there and they're, erm, they know what you're doing. You know? (Jack)

It's helpful just to know he's there... Just to know they're around. (Louise)

Happy. Just that he's still looking over me. I always know that he's always with me. (Mary)

It is difficult to say to what extent such beliefs were inherent on local culture, or to what extent participants fully understood their stated beliefs. However, it is clear that afterlife beliefs were a source of comfort those who held them and that they provided a conduit through which participants could maintain some level of relationship with the deceased. Participants conveyed a sense of not having to let go of their loved one completely, all at once, but being able to hold a part of either the deceased or their relationship with the deceased in their current reality.

3.1.2.5 Life Goes On

One method of dealing with grief that participants' accounts reflected was that of moving on with their life and to some extent forcing themselves to forget about their grief. Interestingly the two participants who stated this explicitly both reside within the same group home. It is unknown whether this is coincidental or perhaps reflects the ethos encouraged by carers or other residents.

Normally it just, you just have to get on with your life so you just get on with it... Well if they were here they would still want you to carry on your life and do your own things. (Jack)

I need to get on with my own life. So I can't stay sad... To try and be positive and get on with your life... It makes me more determined and what not. To get on with my own life. (Katie)

Other participants alluded to reaching a point where they tried to leave their grief in the past through their actions. One participant (Kevin) recounted how he continues to visit the nursing home that cared for his mother before she died, saying *"I still go. Even though my mother isn't there."* Others described how keeping busy and socially active helped them to move on from their grief. Participants generally described this stage of carrying on with their lives as a positive process.

I've not been upset for a while. Because I've been out. I've been visiting lots of people and places. (Matthew)

Because I've got my [activity] in the afternoon. It helps me be busy. (Beth)

I think dad would just like me to carry on. Just what I'm doing - coming here to [day centre]. (Louise)

When you're in among other people you forget about what happened to your mother... I got used to it because I was in amongst a different crowd. And that kept you away from thinking about your folk and everything. It helped because other people were there and, you see, you forget about your mother and

everything. And that helped me. Yes... You just stuck to your [musical instrument] and you forget about what's happened to your mother and that, you see. (Kevin)

This highlights the role of continuing some sense of normality following bereavement. It may be that participants returned to pre-existing activities, or that they took up new interests in order to fill their time. Either way it appears that having the opportunity to 'be themselves' in the wake of bereavement was a positive experience. Perhaps this sense of comfort comes from learning through lived experience that they as individuals, and the world around them, continues to exist in a familiar and predictable manner to some extent, even in the absence of their loved one.

Several participants described there being a role for both remembering their loved one and forgetting them also. The following quote captured the complexity of the task perfectly. When asked what advice he would give to someone whose loved one had recently died, one participant (Jeremy) replied:

I'd tell you to forget... No, DON'T forget again. To ALWAYS remember...To remember as well. A bit of both. (Jeremy)

3.1.3 Level of Inclusion

The second theme that was found to influence participants' lived experience of bereavement and grief was their level of inclusion. Each participant reported a different level of involvement in various aspects of the bereavement process. This level of inclusion was dependant not only on the

extent to which participants were supported and/or permitted by others to be involved, but also on the extent of their own understanding of what had occurred. In relation to level of inclusion, the data provided five sub-themes: communication, predictors of impending death, notification, awareness of practices and ritual involvement.

3.1.3.1 Communication

This sub-theme relates to the sense of having all the relevant information communicated to them or being 'kept in the loop' as it were. Prior to the actual death, participants were kept informed of their loved one's circumstances to varying degrees. Nearly all the participants were able to state how long ago their bereavement occurred, with some stating the exact date.

Three people died in the same year, but different months that year. (Alan)

She died on the 3rd of MONTH... She's been dead for 2 years. (Jane)

He died at the beginning of MONTH last year. (Louise)

More detailed pieces of information such as duration of illness, type of illness and treatment options were less likely to be understood and/or remembered, with participants typically reporting not having had the relevant information at the time, or having been unaware of circumstances.

We didn't find this [nature of illness] out until after the funeral. (Bill)

And I didn't know what it [illness] was although I knew M hadn't been very well but didn't realise it was as bad as it was. (Alan)

Well I didn't know that [he might die] until... well, I didn't know. (Keith)

One participant (Jeremy) described enjoying being able to keep in contact with his mother during her illness so that he could “see if she was ok”. On the other hand another participant (Katie) stated that as far as one relative was concerned she wouldn't “know if she was away [dead] or no”, thus reflecting less contact and communication.

On the other hand, participants who had been kept well informed conveyed a sense of pride at having been included.

I know what happened... I know. (Kevin)

I was the first to be told. (Keith)

This pattern for variable levels of communication echoes that described in relation to participants being kept informed in the lead up to a loved one's death, and that of being given clear information as to the cause of death.

3.1.3.2 Predictors of Impending Death

One way in which many of the participants became aware of their loved one's impending death was by noticing their gradual loss of skills as their health deteriorated. Another commonly stated sign was their loved one having been in hospital.

*It was really a shame because he was always bothered with his leg for walking.
And he had really bad health issues. (Alan)*

*His legs were really thin. Because he had been ill. He had been ill for a while.
And he had been in hospital for a couple of weeks. (Bill)*

*She didn't look like my mum. She was breathing heavily. And she kept on
not... erm... remembering. That's how you knew. And she couldn't talk. And
she couldn't... erm... go to the toilet. We had to help her. We had to get a
special toilet over there. Because she couldn't walk. (Jane)*

*She couldn't, at that time, she had to help me and she couldn't cope. She had
lots of things wrong with her. (Jack)*

*She was like death warmed up. Oh no! She was just away to nothing [thin].
(Katie)*

All the participants who described witnessing their loved one's deterioration conveyed a sense of this being an unpleasant process to observe. This was evident not only in their words and vocal tone but also in their body language and facial expressions. Thus the data demonstrates participants' awareness of the suffering of others, and an interest in their health and wellbeing.

3.1.3.3 Notification

Participants were asked a specific question about how they were informed about their loved one's death. Participants gave a variety of responses which described a range of circumstances. Some were told in person, while others were told over the telephone; some were told while alone, while others were told as part of a group; some received the news from family members, while others were told by care/day centre staff; some were told immediately, while others did not find out until much later.

I got the phone call and dad said that uncle, he's not very well. So I got home as soon as possible... when [work placement manager] got us all through into the canteen where we have our lunch and said "I've got something to tell you."
(Alan)

I got told by the manager in here... He showed me a picture of him and says "Do you remember L?" and I said "Yeah." And he said "Well he was found dead this morning." (Bill)

I only found out because I phoned dad. (Jane)

I was at work here and my mum phoned me on my mobile phone – no actually I was still at school. She gave me a phone call that my granda had died.
(Norman)

I read it in the paper... Yes, her death in the paper... Yes, I found out. And I heard it on the news as well. (Beth)

These are coherent as a theme because they encompass the participants' differing experiences of 'being told' and therefore reflect the wide and varied systems within which PWLD live. It is interesting though that none of the participants expressed an opinion on the appropriateness of the setting in which they were informed. This, coupled with the emergent passive pattern of 'being told' as opposed to 'seeking information' for themselves, suggests an imbalance in the power differential between the informer and the informed, and a culture of the emotional needs of PWLD being afforded less consideration.

3.1.3.4 Awareness of Practices

When talking about common traditions around death such as the creation of a will, having a funeral, burial and cremation, some participants showed an understanding of the function of such traditions. For example, one participant (Jane) described decisions being made about her mother's funeral on the basis of what was "*stated...in the will.*" When asked if her family made the decisions she assuredly responded "*No, MUM decided*", conveying a sense of this being the only just scenario.

Another participant (Norman) showed a full understanding of what a cremation involved stating "*the curtains closed up and the coffin had to slide down and go in the oven and burn.*" Given the potentially distressing nature of

this information it is interesting that he possessed such a full understanding, suggesting that he had not been sheltered from the truth about cremation. Of course, this is based upon the assumption that he understood that the coffin contained the body of his loved one.

In general, participants did not elaborate upon the existence of traditional practices, simply either knowing the terms for customs or not. It is unknown whether participant knowledge of customs stemmed from education on such matters or from exposure to practices through lived experience. It is also unknown whether having an understanding of such traditions mediated their experience of bereavement and grief in any way.

3.1.3.5 Ritual Involvement

As for their involvement in traditional rituals, participants varied in their level of participation in rituals such as viewing the body of their loved one, attending the funeral, visiting the grave, and keeping mementos.

As part of the semi-structured interview, each participant was asked whether or not he/she had viewed the body of their loved one before the funeral. Six participants had seen the body, three of whom chose to visit the restroom, and three of whom were present when their loved one died.

Well it was, just... like... them lying there and... you could... more or less speak to him... and it felt like he was dead... because...well mostly because you are just saying goodbye to him. (Jack)

It wasn't too bad actually... Well she was peaceful and that. (Katie)

Well I went to see my mum's body. I didn't see my dad... I was very upset...but she was just lovely lying there. (Keith)

Well I would've felt it worse if I hadn't seen him... Because he was away. (Mary)

These descriptions provide the first of many references to what could be described as a 'bittersweet' experience; one which holds both positive and negative aspects. While the participants made it clear that to view the body of their loved one was a highly unpleasant experience, they concurrently conveyed a sense that, given the circumstances, it was an experience of value, which they would not wish to forego.

However it was clear that participation in traditional rituals was not something that all the participants found easy to cope with.

When I went in with my auntie I just felt I couldn't go in on my own to see the person. And when I went in to see my granda there was more than one person [with me]... Because you're going in to a room and you don't know what's next or whatever. You just don't know... I would do it again but not by myself. (Alan)

No it wasn't very good to see people when they're like that. You like to see them when they're on their feet. You like to see them then... Not like what's happening there, no, no. (Kevin)

For others such experiences held no positive value and only served to compound their emotional upset. It is unknown what factors mediated this ability to take positive or negative effects from such experiences, but the variation may be a reflection of any number of personal, environmental, or circumstantial factors.

Seven participants did not view the body. One participant (Bill) was clear that this was his personal choice. Six participants did not get the opportunity to view the body of their loved one, with three participants specifically stating that they would have done, given the opportunity.

No I didn't go because it's not actually him... No I know for a fact I wouldn't have gone. (Bill)

No I didn't. No one asked me. (Louise)

I said I wanted to see her body but they wouldn't let me. (Jane)

No. It's up to the staff at [day centre] what they do with me... It would be nice to see her again. Because you wouldn't see her again. So you could remember. (Jeremy)

This further reflects the variation that exists in personal choice when it comes to aspects of bereavement. It also highlights the importance of being provided the 'opportunity', and facilitating choice wherever possible.

All the participants had attended a funeral in the past, and 10 participants attended that of their most recent bereavement. The majority of participants described the funeral as a positive and worthwhile event, while acknowledging the difficult emotions that such an event elicits.

It was alright. I've been there [the crematorium] a few times. (Jack)

It's definitely a good thing to go to the actual service at the funeral and to go and speak to the family. It's definitely good. (Alan)

We were all upset that day... It was scary, kind of. I just felt...I was upset and my sister was upset and my nephew was upset. (Katie)

It's good, going. It was good going to see her, going to the funeral. (Jeremy)

I was upset at the crematorium outside in the car park... It was bad. Just was. Just was... I was sitting at the back of the car. My keyworker came out and got us. I waited in the car. My uncle took us in at the start of the service... No. I don't like them... I felt better after the funeral like. And two of us went to the graves. And we had a big funeral tea for him. (Keith)

You sing "Dust To Dust". I heard that on [TV programme]... It was a good thing to go. I was just there. (Matthew)

This is another example of an experience being 'bittersweet' in nature. Although in itself an unpleasant event, participants were able to find some positive aspects from which to derive comfort in an otherwise undesired circumstance.

Seeing the number of attendees at the funeral, receiving support from others while there, and hearing about the loved one's life story were three things commonly stated as positive aspects of funeral attendance.

This is a thing that I would actually say is a good thing – is how the person was. The kind of things the person liked doing... And you hear about that at the funeral... It was actually good to see the amount of people that made the funeral... It's definitely a good thing to go to the actual service at the funeral and to go and speak to the family. It's definitely good. (Alan)

He was speaking about her. Was it a priest? – I'm not sure – that was speaking about her. About how she was, how nice she was. And how she died... It's good, going. It was good going to see her, going to the funeral. (Jeremy)

If I didn't go I'd have missed all them people... It just showed how much... I didn't think there'd be as many as that... It shows how much he was thought about and cared about. (Louise)

One participant (Jack) described his preference for funerals that feature burials as opposed to cremations.

I don't like the crematorium. You're too hemmed in. I prefer at the grave because you can more easily have your feelings... Well at the grave you can stand there but at the crematorium you're rushed out. And there's too many people... you get more time [at the graveside]. To stand and that. (Jack)

This reflected another benefit that can be gained from funeral attendance given the opportunity – having a sense of being given permission to experience grief emotions, and the time and space required to do so effectively.

Three participants (Beth, Norman and Mary) did not attend the funeral of their most recent bereavement. In one case (Mary) this was her own choice as she believed it would be too upsetting to attend. In the other two cases their non-attendance was due to not having been invited or supported to attend. Both of these participants expressed that this was against their wishes.

No I didn't go. I wish I had. To say goodbye... No they didn't ask me. I wish they had. (Beth)

No I didn't go to the funeral. My mum never – she phoned me and told me that my grandad died and that my family had been to the funeral but not me. I was at school... I HAD to go! Because it's MY grandad [begins to cry]. (Norman)

Both participants conveyed a sense of being prevented from facilitating an aspect of their grief, and an impression of being denied an opportunity that they believed to be rightfully theirs. This provides another example in which an imbalance of power, albeit potentially well-meant, resulted in the repression of an individual's wishes.

Some participants not only had the opportunity to attend the funeral but also had a role to play in proceedings.

I had never done this before but I actually was asked to be one of the... you know when you are lowering the coffin into the ground... but I had never done it before so what I had to do was, so the coffin wasn't unbalanced, I looked at my uncle and I just watched carefully what he was doing and then just gradually let it down... when my gran died myself and my cousin we had to hand out leaflets with the songs in it and her photograph on the front. We gave them out one between two. (Alan)

I carried my dad's coffin and I had a rope to hold at my uncle's funeral. (Jack)

You see I had a cord down at the coffin. I had a certain number. They call out your number when you're lowering the coffin you see... I had to stand at the door of the church and shake hands with everyone when they came in at the door. With my brother. (Kevin)

I was up on the stage and I had words about my gran. (Norman)

Interestingly, all the participants who were assigned a more active role in the funeral were male. This may be due to local customs or gender-role stereotyping. In general, participants described fulfilling such responsibilities

with a sense of pride and duty. In many cases it allowed participants to be openly seen by others as being centrally involved in proceedings, thus acknowledging their right to grieve.

However, being more actively involved in proceedings was not always viewed as a positive experience. For example, having assisted in lowering his father's coffin into the grave, one participant (Jack) felt as though he *"was helping to get rid of him because I helped put him down there. I had the rope."* On the other hand, the same participant felt *"proud"* when carrying the coffin. Thus it is clear that while inclusion tended for the most part to bring comfort and pride, each participant was aware of their own limits, and the point at which they felt overwhelmed by the experience.

In this study, 7 of the participants had visited their loved one's grave and found it to be a positive experience. Of the other 6 participants who had not been to visit their loved one's grave, 5 expressed the wish to do so. They had either not yet been supported to make the visit or did not know where the grave site was. One participant (Katie) said that she did not want to visit her mother's grave believing that it would *"most likely be scary"* and that it held *"too many memories"*. She was unable to elaborate when asked what she thought would be scary about the experience. Again this reflects both the need for relevant information to be passed on and the need to respect individual tolerances.

When it came to keeping mementos of the deceased, all but 2 participants (Bill and Jack) talked about some form of treasured belonging that they kept

by which to remember their loved one. The vast majority of these were photographs of the deceased. One participant (Bill) made no mention of this aspect of grieving, while another participant (Jack) stated that his sister had all such items at her house and so, while he would like to, he did not have any. Of the 11 participants who had photographs of their loved one, 9 described the reminder they provided as a positive thing. Some had the photographs framed in their room, while others carried them on their person. Three participants (Katie, Keith and Jack) described the 'bittersweet' nature of keeping such mementos. Both were able to articulate the happiness that came from seeing their loved one by means of a photograph, while acknowledging the way in which the reminder caused them to miss their loved one more keenly.

I do have some photos but they're old ones... Sometimes I look at them and sometimes I don't... They make me sad. (Katie)

I've got one photo. It's good to have... It's just upsetting looking at it... oh...I don't know... I'm just missing her. (Keith)

I'd probably sit and look at them all. Just have them there... Well you don't know [how they'd make you feel] until you've got them ... Well you probably would think things about them [parents]. You'd probably cry again. Or sometimes, that you've got them there would maybe be helping. (Jack)

This reflects the range of confusing emotions experienced by participants following bereavement and suggests that there is a balance to be found in tailoring one's environment to suit one's own grieving needs.

3.1.4 Continuing Relationship with the Deceased

Another theme which served to mediate the experience participants had of bereavement and grief was the way in which they viewed their continuing relationship with the deceased although no longer physically present. The data provided four sub-themes that contributed to the sense of how participants intended to carry their relationship with the deceased forward: lingering pride, reminiscence, obligation, and yearning.

3.1.4.1 Lingering Pride

Many participants showed that they continued to take pride in their loved one despite them no longer being alive. This suggested that the characteristics they valued in their loved one still held meaning for the participants as they adjusted to a life without their loved one in it.

We've got photographs – but that was the strangest thing – before my grandma died she had taken the time to sort out all the photographs that she had collected over the years. Like from holidays and all that. And my grandpa couldn't get his head around how she'd managed to sort all these photographs into albums!... And we still can't believe how she managed to put all these photographs together. (Alan)

She had a knitting machine and knitted jerseys with the 'Regional [musical instrument] Club' on the jersey... That's not easy you know - putting it on! (Kevin)

You know, on my 21st birthday I got a cuddle from my mum... And she gave me a lot of birthday presents. (Matthew)

Yes we had memories together. Me and my grandad had been fishing together and... old times together. (Norman)

Just how funny he was and witty, and he could do excellent accents. (Louise)

One participant (Alan) described how they made sure to choose a loved one's favourite music to be played at the funeral. Another participant (Jane) made sure to choose her mother's favourite dress for her to be cremated in. Two participants (Jane and Kevin) brought family photographs with them to their interview session and proudly told stories from their loved one's past.

3.1.4.2 Obligation

This sense of pride was echoed in participants' description of feeling obligated to continue to please their dead loved one, whether it be by grieving in a way they would have approved of, maintaining their memory to a 'good enough' standard, or in living life as they would have liked.

So we went down just to see him and see how clean the headstone was. Because you look at some of the headstones and you can't believe how dirty they are. Some of them are so bad that you can't even see the writing!... And we take flowers down to him... I think it's just to show that...like their appreciation of how their thoughts are of the person or something... I suppose as well it shows

the people how much in their life they really miss the person that's no longer with them, you know. (Alan)

I thought it'd be a nice thing to do [to go to the funeral]... Because they probably feel that the person, well, maybe, that's gone, maybe doesn't want you to cry. Things like that... Well if they were here they would still want you to carry on your life and do your own things. (Jack)

I could take flowers down with me to where his ashes are scattered... [It helps] just knowing that he'll be there and he'll be looking down at the flowers. (Mary)

Some participants also described a sense of social obligation to maintain traditional rituals, implying that it would be expected of them by others.

You have to go if somebody died. Somebody – a relative – died... I didn't want to go but I HAD to. That was my DAD. (Katie)

You've got to take them into consideration. Because the way that I look at it is like, if you were to go to a service that someone that you knew, then they would probably go to yours – that sort of thing. Which would be the right way to look at it. (Alan)

This reflects participants' desire to respect the wishes of others, whether out of respect for the subject, or in order to gain the approval of others.

3.1.4.3 Reminiscence

A continued attachment with the deceased was evident by the way in which participants used the opportunity to talk about their loved ones, and to reminisce about the happy times they remembered sharing with them.

I remember him at a Christmas party M had on one of those Santa Claus hats and it was one that lighted up – I can still see him sitting there with his Santa Claus hat on! Because he really enjoyed the Christmas party. He really enjoyed that. And that's what I always say – it's good to remember those times because that's just the kind of guy that he was. (Alan)

It's nice to remember where you stayed. And what she did. And what she did for you. What was nice. And what we did. (Jeremy)

I always think about him at some time every day... Probably because I choose [to]... I just think what he would be doing right now if he was still here. (Louise)

Then Mum always used to – this is long ago days – my mum always used to make toffee, chocolate cake... and she used to clean the screens on the window –

you know the white screens on the window – she did that as well. And she would scratch my head like this [Tickles own head]! (Matthew)

I'd like to talk about my gran – our last times together. We had fun together and 2 excellent daughters after her. She came to stay with my auntie – that's her daughter – all the puppies – my auntie's dogs – we all had fun together, had Christmas together, family together. (Norman)

For the most part, participants described reminiscence bringing them joy, although it could also cause them to miss their loved one more keenly and make their loss seem more 'real'.

I suppose it's good to look back on the happier things that have gone on in your life. Like in the photo albums... it's definitely a good feeling to look back on the happier times. (Alan)

Well I'd say it makes me happy... I've enjoyed speaking to you about my family and everything. Yes, I've enjoyed that... This has been a happy meeting. I like talking about my family. (Kevin)

[It makes me] happy because it's a photo of him with his prize standing at the show. From when he was young and working. It's a nice photo. Happy... it just makes me more happy. (Mary)

[I remember] sad things. That they've died. But sometimes I remember happy things. Sometimes its happy things and sometimes it's sad... Just depends, what, at the time, I'm thinking of. (Jack)

I've got one photo... It's just upsetting looking at it... Her not being here. (Keith)

This highlights the range of emotions experienced by participants in the wake of bereavement, and the long-term nature and lasting effects of those emotions.

3.1.4.4 Yearning

Participants described the way in which their loved one's death left a void of some form in their life, in that they still missed things about them and yearned for the role the loved one played in their lives.

Now I can still see my granda siting in the armchair in the conservatory and once he's read the paper he'll say "What's your news?" And he'll say "What have you been doing?" And I've told him. And my gran – she was the same – she liked to know what was happening. Which I actually thought was – I was glad that they were showing an interest in what was happening and the kind of week I'd had. Because a lot of people don't ask. (Alan)

I miss the things she did... What she did for me... Like taking me to football, or out somewhere. (Jeremy)

The day after I phoned his work – I just wanted to hear his voice one more time. On his answering machine at work. I suppose I'll never get to speak to him, ever... I miss seeing him. (Louise)

Well it always feels strange when I pass his bedroom now and know that he's not there. I know he's not there now, so... I just miss him... I just know that he's not here. I just remember him. (Mary)

I miss the olden days when she used to work... I was just thinking about, wishing my mum was coming back home and to pick me up at my house. (Matthew)

This demonstrates an aspect of grieving that continued to affect participants long after their loved one's death. It also demonstrates the way in which participants were able to keep their loved one 'in mind' despite their no longer being a physical presence in their lives.

3.2 Later Theme Emergence

This ability to look back on an experience with hindsight and deduce its value is an additional theme that emerged towards the end of the analytical process. Having analysed and interpreted the data into themes that

accounted for the lived experience of participants it became apparent that there was still a wealth of data that remained unallocated to any of the main themes. The remaining data was clearly relevant and yet seemed to stand alone in some way.

Upon reflection it became clear that the remaining data differed from that already analysed in the sense that it contained the participants' reflections in hindsight upon their experience. It reflected their ability to evaluate an experience as having been helpful or otherwise, regardless of whether the lived experience at the time was pleasant or unpleasant. Thus, in order to have a complete understanding of the experience of bereavement and grief, participants reflected upon both their lived experience, and their evaluation of that experience.

Aspects that participants described, upon reflection, as helpful were

- attending the funeral;
- visiting their loved one's grave;
- looking at photographs from their loved one's life;
- being around other people;
- talking to other people about their loved one;
- keeping themselves occupied;
- forgetting their loved one (to some extent); and,
- remembering their loved one (to some extent).

Many of these aspects of bereavement and grief had been described in varying terms. While there was acknowledgement of the emotional distress such activities could incur, there was at the same time a description of the

comfort that could be gained from them. This varying description was interpreted as a longitudinal relationship in which, over time, participants were able to look back on their experience, see the 'whole picture' as it were, and make a non-emotive, unbiased judgement as to its worth.

4 REFLECTIONS

This chapter will appraise the research process as a lived experience in itself; firstly from the point of view of the researcher, and secondly from the point of view of the participants.

4.1 Reflexivity

Reflecting upon the experience of carrying out research is an important aspect of qualitative methods. Key to the process of IPA is the researcher's ability to remove themselves from the data and reflect upon their own perception, awareness and consciousness in relation to the subject matter (Smith *et al.*, 2009). In fact, neglecting this aspect of the process has been described as a breach of ethics and tantamount to dishonesty (Ruby, 1980; Shacklock & Smyth, 1998).

Willig (2001) describes two types of reflexivity: 'personal reflexivity' and 'epistemological reflexivity'. Personal reflexivity involves the researcher reflecting upon the ways in which they, as an individual, have influenced the shape of the research. Such influences stem from one's own life experiences and may take the form of values, opinions or interests in relation to the topic being explored. Epistemological reflexivity involves reflecting upon how the personal influences we have brought to the research have impacted upon the study design, data analysis and reporting of findings. The researcher must remain mindful of these processes during the planning, carrying out, and analysis stages of qualitative research. Only by doing so can the research method be said to be transparent and the findings valid.

In keeping with this approach, I¹² kept a reflexive diary of my thoughts as they occurred throughout the research process. I also made a point of recording my initial impressions immediately after each interview. These provided useful reference points for later stages such as analysing the data and appraising the methodology and results.

4.2 Achieving Reflexivity

Given that this was my first attempt at undertaking a qualitative research study, I must admit that the concept of being reflexive in research felt, at first, rather alien to me. I had to date associated reflexivity with clinical practice and not the process of carrying out research. Thus the concept featured heavily in my initial reading so as to be actively adopting a reflexive stance from the outset. The reflexive approach became something of a self-propagating entity as the further I moved into the research process, the more clearly I could see its essential role and value.

4.3 The Early Stages

My initial interest in exploring the topic of bereavement and grief in relation to PWLD stemmed from my clinical experience as both an Assistant Psychologist and Trainee Clinical Psychologist within adult LD services. I had observed a tendency for grief in PWLD to be afforded less care and attention than in the general population. I also recognised the link between unacknowledged grief in PWLD and challenging behaviour as reflected in referrals made to the Clinical Psychology service.

¹² Given the subjective nature of the reflective process it was decided that this chapter would be best written in the first person.

In deciding upon a research question I was aware of there being additional ethical considerations when completing research within the LD population. Given that I was interested in investigating the experiences of bereavement and grief, I knew from my own experience of working in LD services, that such topics, especially in an LD context may be seen as 'sensitive' topics and that I, by probing the topic, may be upsetting a delicate status quo where such issues are not often discussed.

There comes a point in the search for a thesis topic that one's thoughts turn to the ethics panel themselves. One cannot help but be tempted by the idea of choosing an inoffensive topic in the hope that this will be more readily accepted and move more speedily through the early research planning stages. While aware of this temptation, on the other hand, I was also aware of my own desire not to feed into the taboo culture that, from my background reading, seemed to exist around certain topics within the LD population-focussed research base. Taking the reflective process to another level, I admit to being aware of just such a 'rebellious streak' within my own personality and the sense of not wishing to conform by taking the apparently 'easier route' that another topic may provide me.

A further important stage in the reflexive process came when estimating recruitment levels. My aforementioned impression of the taboo nature of bereavement and grief within the LD population and those around them led me to 'expect the worst' in terms of reactions to my attempts to recruit participants. I had read in the literature about the hierarchies of gatekeepers who can make it nigh-impossible to access the population and allow them to make their own choice regarding participation. Perhaps it was this fear of

being rebuffed that contributed to my initial overly conservative efforts at recruitment, which I attributed to responsible, demand-conscious opportunity provision; because in contrast I was also aware of my fear of 'opening the floodgates' as it were – offering a service that I could then not fulfil due to over-subscription. I believed it would be highly unfair to offer the opportunity to talk about something so personal and then have to renege on my offer due to time constraints. At this stage it seemed, ironically, that I was experiencing first-hand the difficulties that I had been forewarned of time and again in the literature as problems inherent to this type of research.

4.4 In The Midst

Being a naïve first-time qualitative researcher, I believed that all my reflexive wonderings would occur during the planning stages of the research and that, once 'on course', with methodology decided, it would be a straight path to the finish. However I quickly learned that the need to remain reflexive continues throughout the stages of data collection and analysis.

4.4.1 Interviews

Before commencing the first interview I was aware of reluctance within myself to cause participants any emotional upset. I envisaged tears and wailing in response to my questions about the loss of their loved one and I envisaged myself being completely unable to contain any emotional response, becoming overwhelmed and feeling utterly helpless. Only through braving that possibility did I learn that this was not a representative response, but rather a reflection of my own fear of 'rocking the boat' within a vulnerable population. Perhaps then I was not immune to the creation of a taboo topic after all as I discovered my own sensibilities! My initial critical

view of others who, as evidenced in the literature, displayed a reluctance to broach such sensitive topics required some readjustment as I discovered the reality of doing just that myself.

I became aware of my own susceptibility to making unfounded judgements of people's abilities when, after talking to one participant's carer, I arrived at the interview with the pre-set notion that the participant would be fairly mono-syllabic in his responses and provide no data of any great worth. Meeting the participant, his quiet nature only rubber-stamped my presumption. However, some of the study's most profound responses originated from this participant and I came away from the interview feeling surprised, but also somewhat ashamed of the way in which I had disregarded someone based upon a third party description and their initial appearance. As it turned out this individual thrived under the one-to-one setting of the interview and, with patience, was able to articulate his most insightful thoughts. Again, I saw mirrored in my own behaviour the prejudices I had originally denounced in others.

I was aware of my emotional response to interviewing participants and how this changed over time. Initially I had expected the interviews to be very emotional and when this turned out not to be the case I think I began to take the significance of the material for granted. It is for this reason then that I was caught unawares by the emotional impact of the third interview and was surprised to find myself tearful on the drive back home. It would be easy after carrying out multiple similar interviews to take for granted the fact that each individual's experience is of utmost importance to them, and deserves respect in its own right.

My emotional response changed again later on in the process when I experienced my own bereavement, mid data collection. I suddenly felt incredibly guilty asking people about such emotive and deeply personal life experiences. I was aware of my reluctance to ask certain sensitive questions, for example about viewing the body of a loved one. However, on reflection, this caused the quality of responses to suffer temporarily, in that I did not allow participants to narrate their experience so comprehensively. I was also aware of my suddenly self-conscious phrasing of questions. My overly tentative wording proved difficult for participants to understand, affecting the connection between researcher and participant. Thus I had to rely upon participant's willingness to talk and their reflections on their interview experience as 'permission' to continue.

4.4.2 Analysing the Interview Material

Analysis of the data seemed initially to be an insurmountable task. This sense of being overwhelmed by the data is commonly cited as one of the difficulties in carrying out qualitative research. The process of getting individual interviews to the point of neat, comprehensive models seemed impossible and I had to force myself to adopt the strategy of breaking the task down into smaller and smaller chunks, rather than viewing it as a whole. This technique actually meshed nicely with the process of coding the data as I already had the mind-set of working with 'trees' and their 'branches' and 'sub-branches' and so on.

In the initial stages of analysis it proved challenging to analyse each interview as an individual entity without being influenced by the content of other interviews. This was helped by reviewing my notes made immediately

after each interview, along with a short description of each participant and their individual characteristics. Reviewing this information allowed me to become re-immersed in each individual account as I was able to relate back to each single interview experience.

The further I got into the analysis the more it became evident that the emerging themes did not always fit uniformly into one model or another, but rather, the data could be arranged in various ways and still make sense. In the end my decision to structure the results as I have done was borne out of instinct and what I felt was the 'best fit'.

Of course it would be impossible for my increasing insight into participants' experiences to not affect, in some way, my view of the data. This is also true of the climate in which I undertook the data in the first place; that of believing this to be a neglected area of need within the LD population. I can only hope that by doing my utmost to remain reflexive during the process I have acknowledged the presence of these influences and made my methodology as transparent as possible.

4.5 Participation Experience

I believe it is important that I not only include my own reflections on the research process but also those of my participants. Intrinsic to the qualitative methodology was the desire to collect feedback from participants on their participation experience. In the early stages of the research this was helpful in monitoring the effect of participation upon participants and in later stages was useful in evaluating the research methodology.

4.5.1 Interview Experience

As part of the semi-structured interview every participant was asked how they felt about the interview experience. On the whole, participant's described it as having been a positive or neutral experience.

It's been alright... I thought it would be alright. (Jack)

Very helpful... No, I'm quite happy. (Jane)

I'm glad that we talked. (Beth)

I'm ok now. (Jeremy)

I feel alright actually. (Katie)

I feel ok. Very relaxed. (Keith)

I've enjoyed talking to you... This has been a happy meeting. I like talking about my family. You have made me very happy today. (Kevin)

Not bad. It has just taken things off my mind a little bit... Just got all the things off of my mind. (Mary)

I'm not upset just now, I'm happy just now. (Matthew)

Two negative aspects that were mentioned included one participant (Beth) saying *"I feel tired now"*, while another (Mary) said *"I'm just sitting here shaking!"* This reflected the effortful nature of talking about bereavement and the drain it places upon one's emotions. Four participants (Matthew, Beth, Norman and Mary) became tearful during their interview. However they all described feeling better towards the end of the session, indicating that the opportunity to discuss their bereavement and grief had provided a useful outlet for their negative emotions.

Having the opportunity to discuss the circumstances around their bereavement gave some participants a chance to set goals for themselves in managing their grief. Three participants (Louise, Jane and Mary) identified helpful things that they had not had the chance to do and they expressed their desire to follow this up.

You've just given me a really good idea! I might plant a plant! I'd have to ask at home. (Louise)

I've made a bench... A memory bench... I've got to sand it down and then repaint, varnish it again... And I haven't got the plaque to go on it yet. (Jane)

I want to [visit the grave]... Not yet. I will do... Yes. I'll tell them [care staff] I want to talk and I want to cry.

It is unknown whether or not participants were able to act upon their wishes following their interview.

4.5.2 Possible Avoidance

During the course of the interviews there were times when it seemed as though participants avoided answering some questions. These questions were, without exception, those that dealt with the most emotive topics such as what it was like to be told their loved one had died, what it was like to view the body, and what it means to miss someone. At times participants clearly expressed their difficulty in answering a question.

I'm not sure what to say... I think I don't know what to say about that. Because it's puzzling. It's confusing to me. (Jeremy)

I don't know. I'm not sure about that. I can't get round that one!... I don't know. That's a difficult question, that is. (Kevin)

At other times participants gave the response “*I don't know.*” This may of course reflect a lack of understanding or incomplete memory, given the

participants' level of cognitive functioning and the complex nature of the topic. However as the researcher I was careful not to press the participants for responses as I viewed their opportunity to remain silent as a form of communication in itself (Giami, 2001).

One participant (Katie) explicitly described her conscious protective strategy, stating *"I didn't want to get upset because I've not to overdo it, you see. So I don't get ill."* One participant (Matthew) routinely changed the subject when he could not answer a question, while another (Kevin) consistently broke into nervous laughter. This may be evidence of unconscious functional coping mechanisms that protect one from the negative emotions associated with such difficult topics.

At the early stages of this study I admit to having expected some interviews to be unsuccessful, either through participants being unwilling to share their experiences or becoming too emotionally upset to continue. However, even though there were tears during some interviews, none of the participants at any time expressed that they were finding participation distressing or unhelpful. Even those who appeared cautious to begin with described the experience as pleasant and helpful in some way.

What struck me most about the participants' reactions to being interviewed was their gratitude at having been afforded a segment of time, just for them, in which they could be the narrator of their own experience. As the researcher I noticed within myself, perhaps through reactive transference, a sense of being privileged to be party to such private information (Johnson,

2009). Any initial concerns about whether or not I would have the skills to contain such disclosures were quickly replaced with the realisation that it was not so much what individuals wanted to express that was important to them, but rather having the opportunity to tell their story.

5 DISCUSSION

This chapter will begin with a summary of the main results from the current study. The theoretical implications of the study will then be considered in relation to the relevant literature. Clinical and ethical implications of the current findings will also be outlined, followed by a consideration of the methodological strengths and limitations of the current study. Finally, areas for future research will be described, followed by a short conclusion.

5.1 Summary of Results

The current study aimed to investigate how adults with mild LD experience bereavement and grief. A purposive sampling method was used and participants were recruited through day service providers in the local area. Thirteen participants (8 males and 5 females) were recruited, ranging between 20 and 72 years of age. Each participant took part in a semi-structured interview in which they were asked to describe a recent bereavement experience.

The qualitative analysis methodology of IPA was used to analyse the interview transcripts. This resulted in 4 main themes, each with their own sub-themes, which the researcher felt best encompassed the configuration of the participants' experience. The four main themes provided contextual information within which to understand an individual's experience of bereavement and grief. An individual's experience was best understood in the context of their 'intra- and inter-personal experiences', 'core beliefs about life and death', 'level of inclusion', and 'continuing relationship with the

deceased'. This coupled with later 'evaluation of their lived experience', enabled participants to come to an overarching 'understanding of their entire experience' of bereavement and grief.

Therefore, the findings of the current study suggest that adults with mild LD experience bereavement and grief in a manner much like the general population, in that they are affected by their bereavement-related intra-and inter-personal experiences, are sensitive to a wide range of oscillating emotions, are subject to the same (if not more) losses, and hold similar values when it comes to maintaining their relationship with the deceased.

Critics may argue that these results are less than surprising given that, by the nature of their mild LD, participants could be said to be not very different from the general population to begin with. However, as reflected in the wider literature, there are various ways in which PWLD could be said to be distinct in their psychological and experiential make-up. Differences have been shown in how PWLD form attachments, experience emotions, and perceive the world around them. These differences may be inherent to having LD, or they may come about through the environmental influences constructed by society. What the current study shows is that despite differences in cognitive functioning, emotional maturity, social opportunities, and levels of support, PWLD do acknowledge bereavement and do experience grief, and they do so in a manner that is not so far removed from what is classed "the norm". The focus then should be upon how PWLD can be effectively supported in best experiencing and processing such life events (Raskind *et al.*, 1999).

5.2 Reflection upon Themes

Each of the main themes will now be considered with reference to the relevant literature. It is acknowledged that there are many ways in which the themes below overlap in their content and implications. However to expand on each sub-relationship is out of the scope of this thesis and so that researcher chose to highlight the main reflections only.

5.2.1 Reflection upon 'Intra- and Inter-Personal Experience'

This theme reflected the reality of participants' lived bereavement experience from the standpoint of both intra- and inter-personal factors. This encompassed experiential factors that proved to be important to participants whether they be experienced in isolation within oneself, or in combination with others around them as a socially shared or socially dissonant experience.

As far as intra-personal experiences are concerned, a notable feature of the participants' narratives was their ability to describe their experience despite their sometimes limited vocabulary. This was assisted by the use of expressive body language, facial expressions, and changes in demeanour. The ability to effectively communicate affect non-verbally has been shown to be unrelated to level of cognitive functioning (Nowicki & Duke, 1994).

Where participants showed more difficulty in articulating their experience was in relation to labelling their emotional experience. Often, participants would begin to expand upon what they meant by descriptions such as "*sad*" or "*upset*", only to find that they did not have the words to enunciate further. Participants often fell back upon responding with "*I don't know*" or simply

becoming silent. Some were able to describe their inner feelings using concrete examples (e.g. like being in an empty room). In general PWLD have been shown to be able to reliably label emotional experiences (Lindsay *et al.*, 1994). However the results of the current study suggest a deficit in emotional vocabulary, which at times led to feelings of frustration and isolation. This has implications for the incidence of challenging behaviour in PWLD following bereavement given the communicative function that such behaviours can serve (Emerson & Bromley, 1995).

Participants described an 'oscillation' between emotional states during their grief. This fits with stress response theory (Horowitz, 1986) and Stroebe and Schut's (1999) suggested Dual Process Model of grief, where the opposing roles of intrusion and avoidance serve as a regulatory mechanism within which grief is managed. This oscillation continues until a point of habituation, and therefore adaptation to loss is reached (Greene, 2002). It is unknown whether participants who described this oscillation in emotions between 'remembering' and 'forgetting, or feeling 'sad' and feeling 'better', would describe their eventual emotional state as satisfactory in terms of grief outcome. Certainly there were instances when participants described being surprised by the strength of their emotional reaction some time after their bereavement, which suggests a state of contentment and/or acceptance had not yet been reached.

A further area of theoretical interest is that of participants' descriptions of the inter-personal aspects of their bereavement experience. Many participants described not only their own experience but also that of others around them. This was especially evident in the described changes in role and level of

responsibility. Participants described the effects of bereavement upon other family members, friends, fellow service users and carers. They also described how the grief reactions of others impacted upon them, and how their position within their social support network became changed. In addition, several participants alluded to how organisational factors made their experience more difficult, through lack of resources and obstructive practicalities. Much of the literature on the systemic impact of bereavement is tailored towards the traditional family model, but such theory is equally applicable to individuals living within residential community projects (Smyly, 2006).

5.2.2 Reflection upon 'Core Beliefs about Life and Death'

This theme encompassed participants' views on the cycle of life. Participants described their expectations of both life and death. They also expressed their opinion on the fairness of death, and their beliefs regarding what happens after death, both for the deceased and the bereaved.

Participants were not asked directly to portray their understanding of death. Rather, insights could be drawn from their experience descriptions. Every participant evidenced some form of belief system that, for them, made sense of the processes of death and dying. With reference to the suggested components of a death concept, that of finality, non-functionality, causality, and universality (Adams & Deveau, 1995), participants showed some understanding of all of these concepts.

In relation to the concept of finality, many participants referred to knowing they would never see or talk to their loved one again. This was reflected in

their description of feelings of loss; they described, not a temporary forfeiture, but an irreversible change in circumstances. Often it was in relating their appreciation of this concept that caused participants to describe the strongest emotional experiences.

As regards non-functionality, this concept was less well-evidenced in participants' responses. Some made reference to their loved one being 'asleep' but this was generally seen in participants who had had the opportunity to view the body of their loved one. Perhaps the concrete evidence provided by such an experience provided the best means for participants to comprehend the concept of non-functionality. On the other hand, many participants expressed a belief in their loved one still existing in some other form. It may be that to hold this belief is incompatible with one of non-functionality.

Causality was the concept best represented in participants' responses. Every participant reported some root cause that they believed to be responsible for their loved one's death. Some provided medically-sound explanations, while others made the best of the information they had in constructing a causal relationship.

Universality was the concept most clearly associated with level of functioning. This reproduces the findings of McEvoy (1989). Although no standardised measure of ability was used in the current study, the researcher's past clinical experience enabled her to form some impression of each participant's cognitive functioning in relation to that of other participants. Only 2 participants referred to mortality as applied to the

general population, with most stating that they had "*never thought about it*" before. The most common scenario was for participants not to have anticipated the possibility of death until it was upon them, in some cases despite being forewarned by others. This may reflect a form of avoidance where the emotional magnitude of such issues is too much to contemplate if not required to. On the other hand it may be that the structure of the interview itself resulted in an unfair representation of the understanding of universality, seen as the focus was upon past bereavements and not the concept of mortality in general.

Responses demonstrated that participants developed many of their attitudes based upon past life experiences, be they death-related or otherwise. For example, someone who had experienced bereavement in the past may have had an idea of what to expect, whether in relation to the nature of the death itself, one's own emotional experience, or the reactions of others. On the other hand, if an individual had little past experience with bereavement and grief they tended to have a sense of not knowing what to expect in the aftermath of bereavement.

Participants showed the ability to adapt their view of the world if their experiences proved to be incongruent with their expectations. This process can be understood in the context of learning theory. Learning theory accounts for the way in which current and future events mould our expectations as we learn of other possible ways in which to experience the world (Hartley, 1998). According to his equilibrium model of learning, Piaget (1977) described how an individual forms a comprehensive view of the world by means of incorporating new, previously world-model-incongruent

information, in order to reach re-equilibrium and cognitive development. Such mechanisms are echoed in more recent learning theory such as transformative learning (Mezirow, 1991).

However, just because a participant had a novel experience of the manner in which a loss can occur (e.g. someone dying young) this did not necessarily mean that he or she would absorb this new experience into their knowledge base and accept it as expected and fair. Rather, participants voiced their feelings regarding 'unacceptable' outcomes that left them with feelings of dissatisfaction that endured over time. This suggests that the acquisition of new knowledge is not as straightforward as experiencing, learning and accepting, but that other personal values interact and affect an individual's final perspective.

This indicates a role for attitudinal factors. It has been suggested that attitudes formed on an emotional basis will be more resistant to change than those based upon cognitive information alone (Edwards, 1990). Therefore it could be said that the emotional affect component of bereavement experiences make it less likely for related attitudes or schemas to adjust solely due to experience over time. On the other hand, perhaps this is yet a further example of how the very individual nature of grief makes explanation by means of a prescriptive model difficult. What is clear is that PWLD are capable of forming their own opinions on life and death, when provided with sufficient appropriate information and relevant experiences.

These findings echo the suggested profile of abilities provided by Meeusen-van de Kerkhof *et al.* (2006) who proposed that individuals with

mild LD are generally capable of defining themselves and their environment, recognising social norms, possessing a view of the world, and identifying cause and effect relationships.

5.2.3 Reflection upon 'Level of Inclusion'

This theme reflected the level to which participants were party to enough information to feel informed of, and involved in, the bereavement process. Due to communication barriers, both actual and society-imposed, such information was often inaccessible to participants directly. Rather they described being reliant upon others to share information in an appropriate accessible form. It was unclear from participant accounts how likely they were to be provided with full and accurate information. It is also unknown to what extent participants would benefit from being fully informed, but the data suggests that there would be individual differences in terms of how much information individual participants felt able to cope with.

What can be deduced is the way in which participants' perception of inclusion influenced their having some sense of control in an otherwise helpless situation. Participants were powerless to reverse their loved one's death, however some conveyed a greater sense of peace and acceptance with this reality than others. Those who were able to justify their emotional experience by way of factual information (for example, I felt sad because I knew X was ill) conveyed a better sense of being connected to the entire bereavement experience and having a greater sense of control over it. This may be linked to the extent to which the loss came as a shock, and the extent to which participants were able to, in some measure, prepare themselves in advance.

Research in the general population suggests that individuals who are more prepared for their loved one's death will experience less distress and will be less likely to experience mental health problems following bereavement (Barry *et al.*, 2002). However measurement of 'preparedness' is fraught with difficulty. Some researchers assume a correlation between advance warning and increased preparedness (O'Bryant, 1991), while others rely on the manner of death in terms of predictability (Rynearson & McCreery, 1993), or subjective ratings of preparedness (Herbert *et al.*, 2006). There are various other variables to control for such as the relationship to the deceased, premorbid mental health, and individual attitudes, thus making the development of a true measure difficult (Neimeyer *et al.*, 2004).

However what was clear from participants' accounts was that they preferred to be kept informed of their loved one's health, the manner of their death, and the arrangements afterwards. Those who were not apprised of such information and therefore opportunities to grieve voiced a sense of additional losses as they missed out on key parts of mourning rituals. This provides evidence against concerns that involvement in such rituals is beyond the abilities of PWLD (Hollins & Esterhuyzen, 1997).

5.2.4 Reflection upon 'Continuing Relationship with the Deceased'

This theme explored the extent to which a dead loved one continued to play an important part in participants' lives. Participants described taking comfort from the idea that their loved one was still present in some other form. They also reflected the importance of calling to mind their past relationship with the deceased by means of reminiscence and keeping mementos.

This challenges early psychoanalytical grief theories which assumed that complete severance of all ties to the deceased was essential for a positive grief outcome (Freud, 1917). Rather, it reflects the stage of grieving suggested by the likes of Marris (1992) and Worden (2009) where there is a role for extraction of the important aspects of a lost relationship which then continue to play an important part in the bereaved's new reality.

On the other hand, studies have found that not all forms of continuing bond are indicative of a positive outcome. Field *et al.* (1999) found that the manner in which one maintains their bond with the deceased impacts upon their grief experience. For example, they found that keeping the deceased's possessions is more likely to indicate increased levels of grief, while sensing the deceased's presence is not. Of course this assumes that to experience a high level of grief is in itself maladaptive and does not take account of the mediating role of attachment (Field & Sundin, 2001). Field *et al.* (2003) went on to conclude that the important variable is the extent to which the bereaved fixates upon their continuing bond rather than adapting to their new reality.

The concept of 'fixation' upon one's continuing bond with the deceased seems to be a more logical measure of adaptiveness (Shut *et al.*, 2006). It is clear how an individual who continues to focus upon their relationship with the deceased to the detriment of adapting to their new reality may struggle to resolve their grief effectively. This is reflected in the results of the current study where participants stressed, not only the role of the continuing bond, but also the importance of moving on with their lives and relegating their

continuing bond to some extent, thus finding a balance between being either dismissive or preoccupied (Shaver & Tancredy, 2001).

This theme also provided strong evidence to prove that PWLD have the capability to form emotional attachments. Not only did participants show evidence of having formed strong bonds, they also demonstrated the ability to adapt these bonds in the wake of physical loss, so as to maintain some sense of connection.

5.2.5 Reflection upon 'Evaluation of Lived Experience'

This theme incorporated participants' reflections upon all facets of their bereavement experience. It reflected their ability, with time, to step outside of their own experience and evaluate various aspects from a less emotional standpoint. This links back to Piagetian theory where experiences are incorporated into, and mould our view of the world around us (Piaget, 1970).

What was particularly striking in participants' accounts was their ability to extract the usefulness of a grieving activity despite its intrinsic capacity to cause them emotional upset. For example, if a participant attended the funeral they were able to describe the negative emotional experience, while still acknowledging the benefit it provided them in terms of support from others, an opportunity to say goodbye, and some level of satisfaction at having been there. It could be said that this extraction of the positive came about solely through hindsight and that participants were able to reflect back once in a less emotional state of mind. However the fact that participants who missed out on such events were also able to identify the way in which

they would have benefitted contradicts this theory. Rather participants were able to infer the usefulness, despite not having experienced it directly.

This is reminiscent of the tasks of grieving believed necessary to achieve a positive grief outcome, specifically that of 'finding benefit' (Davis et al., 1998; Janoff-Bulman & Frantz, 1997). Some participants were prevented from achieving this sense of the value of an event in their life, being unable to actively grieve as they wished. Several participants described being 'left out' of certain aspects of grieving rituals, and it was evident that not all salient information was passed on to participants. Nor were their wishes always facilitated by those supporting them. This often prevented participants from completing some of the common tasks of grieving.

5.3 Ethical and Clinical Implications

The results of the current study suggest that in order to provide a healthy and helpful culture around bereavement for PWLD, several systemic factors need to be in place. There already exists a range of suggestions as to what should be included in grief-focussed intervention for PWLD, many of which conform to a similar model; one of systemic support (James, 1995; Read & Elliott, 2007; Stoddart & McDonnell, 1999). This is well illustrated by Read and Elliott (2007) by the use of a 'continuum of support' model. They suggest that supported grief work involves several stages, namely

- education (general preparation around loss and its effects);
- participation (being included and involved in the death culture);
- facilitation (acknowledging and individual's grief and assisting them to learn new coping strategies); and,

- therapeutic intervention, as required (recognising bereavement difficulties and helping the individual access appropriate professional support).

These suggestions are successive in nature in that they move from universally adopted, non-personal cultural practices, to focussed, individually-tailored interventions.

5.3.1 Culture of Openness

Before looking at more actively implemented clinical endeavours, the results of the current study suggest that, in order to best prepare PWLD to deal with bereavement when it occurs, there needs to be a general culture of openness when it comes to the realities of death and dying. This should be promoted regardless of whether it is anticipated that an individual will experience an impending loss. This means taking advantage of everyday opportunities to make PWLD aware of the life cycle, rather than shielding them from the reality. Suggested methods include drawing attention to the laws of nature or 'circle of life' as it occurs in nature. Attention can be drawn to the life cycles of plants and animals, and also to that of humans. This may be through real life experience or through other medium such as television, books, and magazines (Read & Elliott, 2007). This promotion of awareness may to some extent habituate PWLD to the occurrence of death and lessen the shock and confusion of death when it occurs in one's reality.

5.3.2 Education

A more active clinical endeavour is that of specific education around death and dying. This is not a form of bereavement counselling, but rather basic education, regardless of participants' bereavement experience history or

anticipated future. Much of the literature looks at group work in the form of interventions provided in the wake of bereavement, with little focus upon generic education provision for PWLD. Read & Elliott (2007) are one of the few to recommend the provision of a planned educational programme regardless of participant experience of death. They suggest that there is a need for government guidelines in the form of training initiatives for this method to succeed. Suggested topics therein include lifecycle work, education on feelings and emotions, looking at culturally relevant practices, and exploring the wider issues of loss, transition and change.

Hollins *et al.* (1989) produced a series of social stories with which to introduce the subject of death and to outline the typical practices following bereavement such as attending a funeral and keeping mementos, and these resources continue to be updated so as to stay current (Hollins *et al.*, 2004). Social stories can prove powerful tools with which to help an individual understand the concepts of death and dying (Summers & Witts, 2003). They later produced a resource pack adapting the material for a group therapy setting, along with a video entitled 'The Last Taboo' in which individuals relate their bereavement experiences. Such material can be used to prompt group discussions and to normalise grief reactions. Other suggested educational media include the use of life-story work, family trees, artwork, drama, and poetry (Read *et al.*, 1999).

A pilot study which trialled death education in PWLD showed that participants did benefit from death education, in that they obtained better scores on a measure of knowledge and attitudes to death (Yanok & Beifus, 1993). It was hypothesised that the process of education itself served as a

form of 'graded exposure' to the realities of death, suggesting that PWLD would develop 'tolerance' to the distress of bereavement and would be able to practise appropriate grief responses via the modelling of behaviour. Similar evidence of improved performance following training has been described in emotion recognition (McKenzie *et al.*, 2000).

However this raises the question of whether true 'learning' occurs through such education, or whether in fact PWLD simply recognise what is expected of them, and thus provide the 'right' answers and behave accordingly. It is difficult to generalise such results to a real-life bereavement experience. It is this sort of methodological problem that highlights the need for direct evaluation by PWLD themselves, and thus the benefit of qualitative exploration as a true subjective measure of personal experience.

5.3.3 Inclusion

When PWLD do experience bereavement it is important that they are included in as much of the process as possible. This includes being provided with sufficient information in the lead up to a loss so as to promote some feeling of 'being in the know', being provided with timely and sensitive notification of a death, and being allowed to participate in bereavement rituals along with others. Inclusion also allows for PWLD to form their own opinions regarding their preferences and wishes in how to deal with their loss and resulting grief.

Participants also stressed the importance of choice. They described having no use for prescribed methods of mourning, or set expectations of how they ought to deal with their grief. Rather, they communicated a desire for choice,

even if that choice was related to the simplest aspects of their bereavement experience. The notion that 'one size fits all' was firmly disproven by participant accounts. The relationship between choice and better quality of life has been well-documented (Brown, 1997; Department of Health, 2001; Neely-Barnes *et al.*, 2008; Wehmeyer & Schwartz, 1998).

This has implication for those supporting PWLD. It requires families and carers to set aside their own beliefs of what may or may not be 'appropriate' for the individual, and to allow them to make that judgement for themselves. This may be made more difficult by a carer's own personal preferred grieving style. The reluctance of many to participate in the current research reflects not only the reluctance to acknowledge grief in PWLD, but also perhaps the general population's own reticence towards the realities of death and dying (Walter, 1991). Due to their lesser autonomy PWLD may be more likely to become subject to the preferences and sensitivities of those supporting them. This was reflected in participants' descriptions of having their wishes denied, and the sense of powerlessness to remedy this situation.

5.3.4 Facilitation

The results of the current study suggest that it is not enough to simply provide bereaved PWLD with the relevant information regarding a loss and to hear their wishes. Participants asked for facilitation of choice by respecting their personal opinions and beliefs. It is of little value to hear an individual's wishes if they are not facilitated and followed through. Due to a combination of real and society-imposed inequities participants were often unable to put their own wishes into effect on their own initiative. Rather they relied upon the support and assistance of others, with the potential to be left feeling

helpless and unfulfilled if not made reliably available. Of course, it is worth noting that neither choice nor the facilitation of such choice is possible at all in the absence of successful communication.

Of note in the current study is the way in which participants described a higher level of facilitation in the early stages post-bereavement, but difficulties in continuing to facilitate their expression of grief over time. For example, practices such as viewing the body and attending the funeral were fairly well represented within participant accounts. However the area that participants' needs tended to be neglected was in establishing a routine of regular acknowledgement of their loss by means of rituals such as visiting the grave site, or recognising annual memorials. The resources required to achieve these aims, such as information about the grave site, transport to the grave site, access to mementos, and the opportunity to reminisce were areas that seemed to be most neglected in terms of facilitation by others. This may reflect issues such as carers struggling to find a balance between facilitating choice and fulfilling their duty of care, the perhaps unconscious impact of the carers' own beliefs, and lack of appreciation for the long-term and wide-spread effects of bereavement upon PWLD (McKenzie *et al.* 1999; Pockney, 2006; Smyth, 2006)

5.3.5 Support

When it comes to providing support for PWLD following bereavement the results of the current study suggest that rather than seeking any in-depth or complicated grief counselling, PWLD simply want to have the opportunity to express their feelings in an unpressured, unbiased manner. Participants demonstrated a desire to be heard. Contrary to the expectations of others

(MacHale *et al.*, 2009), participants' primary need was not to receive some form of therapeutic intervention or emotional comfort, but rather to be granted the opportunity to express themselves freely in an impartial, consequence-free environment. Equally, their sole demand of such a resource may be to communicate that they have no need of it. Either way, the opportunity alone was described as beneficial and appreciated.

Suggested means by which to provide support for PWLD include the undertaking of bereavement-related projects such as life story, memory, and emotions work (Read & Elliott, 2007). However there are difficulties related to the implementation of such measures. A study by Dowling *et al.* (2006) highlighted some of the difficulties involved in delivering bereavement specific support in the community. They randomly assigned PWLD to either a bereavement-counsellor facilitated therapy, or an integrated intervention delivered in the community by their carers. They highlighted not only the difficulty in recruiting carers to the latter intervention, but also the difficulties in ensuring the intervention was delivered effectively. The integrated intervention required carers to carry out loss-oriented activities with individuals, such as reminiscing about the bereaved, looking at photographs of them, and visiting the grave site. The carers for exactly half of the sample withdrew from the study citing concern for the individual's well-being. For those who continued to be involved, it was noted that the intervention was given low priority among carers and was inadequately delivered. This resulted in no positive change in participants' grief presentation, and even a worsening in pre-intervention emotional and behavioural problems. Interestingly, much more positive results were achieved for the group allocated to external bereavement counselling. This

may be a reflection of lack of carer confidence in carrying out such work, but could also reveal carer biases towards educational versus practical support.

5.3.6 Intervention

It would be remiss not to acknowledge the need for formal intervention in assisting some PWLD to deal with their grief. While it is clear that not all PWLD who experience bereavement will have need of some form of grief intervention (Elliott, 1995), there will be individuals who, due to personal or systemic factors, will require some form of grief counselling.

Cathcart (1995) advocates the use of group versus individual grief therapy specifically for its normalising effect and the way in which it provides participants with a forum to expand upon discussion topics. An example group format is presented by Persaud and Persaud (1997) who suggest covering the topics of loss, mourning, feelings, funerals, crematoriums and cemeteries, cultural aspects, wills, and feelings of anger. Several other studies suggest a similar format and topic list (James, 1995; Summers & Witts, 2003

There is much written on the principles behind delivering such interventions and the methods for delivery themselves (Hollins, 1995; Meeusen-van de Kerkhof, 2006; Read, 2001; Read *et al.*, 1999). Read *et al.* (1999) draw attention to the particular approaches required when delivering a grief counselling intervention for PWLD. They stress the need for bereavement counselling interventions to be flexible in approach, be willing to address challenges, and to listen to the needs of the clients as well as the needs of the counsellors themselves. These recommendations mirror the qualities reported by participants as being the most useful in providing support. Only by putting

in place such collaborative and sensitive methods will facilitators gain access to the true world of the bereaved.

5.4 Methodological Critique

The current study will now be evaluated in terms of methodological strengths and limitations, with consideration given to how the study could be improved.

5.4.1 Strengths of the Current Study

One of the major strengths of the current study is that it succeeded in accessing first-hand accounts of individuals' experiences. This produced a two-fold advantage; firstly for participants, and secondly for the research itself. In being able to talk about their experiences, participants developed a sense of ownership and confidence in their narrative, and had a sense of having contributed something useful. The quality of the research also benefitted in that accounts were, as far as possible, unedited, unguided, and unbiased, thus resulting in a purer representation of the target population's lived reality.

An unexpected strength of the study was the benefit that it provided to participants. Almost unanimously, participants described having enjoyed their research experience. For some it allowed them to unburden themselves of weighty emotional issues, while for others it afforded them an opportunity to reminisce about their loved one. Therefore, without meaning to, the research process itself provided support to the participants.

5.4.2 Limitations of the Current Study

This study has several limitations. Firstly, the method of participant selection did not include a measure of cognitive ability, but rather was based upon clinical judgement and the opinion of others who knew the participants well. Therefore it is difficult to say with certainty that all participants fell within the mild level of LD (IQ = 50-79). Appropriate screening tools that could have been used include the British Picture Vocabulary Scale (4th Edition) (BPVS-IV) and the Wechsler Abbreviated Scale of Intelligence (WASI). These are both relatively short assessments that would have been quick to administer at the recruitment stage.

Methodological strength could be added to the current study by formalising the exploration of the literature in the introduction section by applying a quality assessment framework, in the form of a peer-reviewed protocol, in order to produce a systematic literature review. This would ensure a fully rigorous examination of the available relevant literature, and result in impartial and comprehensive results. This level of scrutiny was did not fit with the thesis model chosen by the researcher, as the sole intention was to make transparent the researcher's reasoning in identifying the need for a research study utilising the current methods. Therefore a narrative review method was deemed fit for the current study, given its exploratory purpose. The researcher intends to carry out a systematic review procedure in due course and publish the findings as a separate piece of work.

Due to the time constraints upon the current project, the opportunity for triangulation of participant accounts was limited. Ideally, the researcher would have checked back with participants on her interpretation of their accounts. Instead this was done continually, during the interviews, by using

summary statements and 'checking back' with participants (reflecting) at the time. This technique avoided the possibility that a subsequent visit to check responses would suggest to participants that they had done something wrong or needed to change their responses. In addition, due to their LD, participants may have been unable to remember the details of their interview if asked at a later date.

It could be argued that, given the methodology employed, it is impossible to generalise findings to the wider population of PWLD. This is true to some extent in that participants represented individuals towards the more cognitively able end of the LD continuum, and therefore results may differ significantly for those of lesser cognitive ability. On the other hand, considering only adults within the mild LD range, the relatively large sample provided a wide range of experiential accounts and subsequent analysis suggested theoretical saturation. Further research would have to be carried out to explore the experiences of individuals with moderate, severe and profound LD.

The method used in the current study does not control for longitudinal effects. Participants did not all experience their bereavement at the same time and therefore the sample represented individuals at various stages of grief. That being said, ascertaining where someone 'is at' with their grief is not as simple as measuring time since bereavement and so controlling this variable would be difficult to do accurately. Further, the exploratory nature of the study did not require such stipulation.

5.5 Possible Future Research

The researcher plans to condense the findings into the format of a journal article and will then seek publication in a peer reviewed journal within the field of LD. The researcher also plans to carry out focus groups at various services in the local area in order to feedback findings to the family and carers of the participants involved (and others). This sort of approach to dissemination is indicated as being more effective in bringing about the application of research findings than more passive techniques, such as publication alone (Bero *et al.*, 1998).

Future research could further the objectives of the current study in several ways. A longitudinal study could be carried out in order to measure change in grief experience with time. For example, participants could be re-interviewed at various points post-bereavement in order to access 'real-time' experiences, rather than relying upon recall. This form of methodology provides valuable data as to the prevalence and temporal evolution of bereavement and grief experiences and can be used to make further links regarding the nature and likelihood of a positive grief outcome (Byrne & Raphael, 1994).

The current study did not control for level of past bereavement experience. A future study could explore any links between level of past experience, education, and support upon subsequent bereavement experiences. The same could be done for levels of attachment or challenging behaviour. It may be that different attachment styles moderate grief experiences in PWLD (Stroebe *et al.*, 2006), or that PWLD who display higher levels of challenging behaviour are less likely to receive support in the wake of bereavement due to the attribution bias of others (Weigel *et al.*, 2006).

Given the success of the current study, it would be interesting to repeat the methodology with a sample of less cognitively able PWLD, perhaps those in the 'moderate' LD range. This may require more use of communication aids and more imaginative interview techniques, but may shed more light upon the links between cognitive ability and the experience of bereavement and grief.

5.6 Conclusion

The current study sought to shed light upon how adults with mild LD experience bereavement and grief. Qualitative analysis revealed that an individual's lived bereavement experience is mediated by their intra- and inter-personal bereavement experiences, their core beliefs about life and death, their level of inclusion, and the way in which they maintain a continuing relationship with the deceased. Participants also showed an ability to evaluate their lived experience in terms of having been helpful or otherwise.

The findings suggest that individuals with mild LD experience bereavement and grief in a manner much like the general population, in that they experience a wide range of oscillating emotions, are subject to the same (if not more) losses, and hold similar values when it comes to maintaining their relationship with the deceased. The results highlight the need for a system of support around PWLD who have experienced bereavement, consisting of a culture of openness regarding death and dying, standardised basic education about death and dying, inclusion in all aspects of bereavement, the

facilitation of informed choice, and support and structured intervention where required.

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7 APPENDICES

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Appendix 1 - Confirmation of NHS ethics not required

NRES Committees - North of Scotland

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558474
Facsimile: 01224 558609
Email: nosres@nhs.net



13 October 2010

Dr Robyn McRitchie
Learning Disability Services
Elmwood
Royal Cornhill Hospital
Cornhill Road
ABERDEEN
AB25 2ZH

Dear Dr McRitchie

Full title of project: **How do adults with mild learning disabilities experience bereavement and grief? A qualitative exploration**

Thank you for seeking the Committee's advice about the above project.

You provided the following documents for consideration:

Document	Date
Protocol	06/10/10

These documents have been considered by the Scientific Officer.

After review of the protocol, the project is a research project and is not an audit or service evaluation.

However, as participants are being recruited from out with the NHS the project does not come under the Remit of the NRES Committees and does not require review by the NHS Ethics Committees.

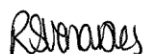
You should check with NHS Grampian what other review arrangements or sources of advice apply to projects of this type. Guidance may be available from the clinical governance office.

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

Yours sincerely

A handwritten signature in black ink, appearing to read 'R Venables'.

Rachel Venables PhD
Scientific Officer

Appendix 2 – Confirmation of R & D approval

Research and Development

Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB



Mrs Robyn McRitchie
Trainee Clinical Psychologist
Elmwood
Royal Cornhill Hospital
Cornhill Road
Aberdeen
AB25 3BW

Date 21/12/10
Our Ref 2010MH006

Enquiries to
Extension 51121
Direct Line 01224 551121

Dear Mrs McRitchie

Management Approval for Non-Commercial Research

REC Ref: Not required
Project title: How do adults with mild learning disabilities experience bereavement and grief? A qualitative study

Thank you very much for sending all relevant documentation. I am pleased to confirm that the above project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Approval to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

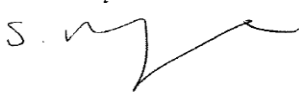
It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments (particularly a study extension)
- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Approval, please do not hesitate to contact the office.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Ridge', with a stylized flourish extending from the end.

Susan Ridge
Business Development Officer

Cc: Dr Karen McKenzie, Academic Supervisor, University of Edinburgh

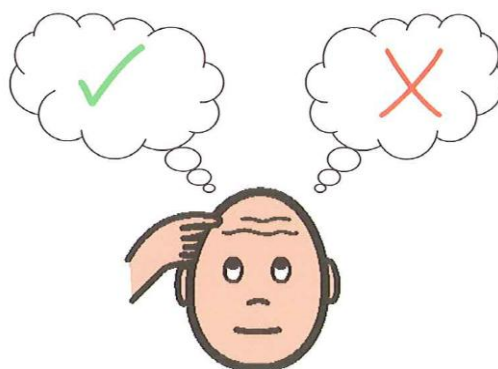
Appendix 3 – Participant Information Sheet

Information Sheet

I have come to see you because someone you know died
and you want to talk to me about it. The person who died
was

I am going to tell you what will happen next.

Remember it is your choice whether or not to join in.

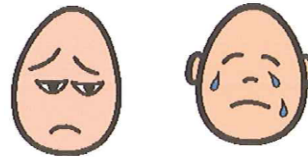


What will it be like?

When we talk, you might feel good.



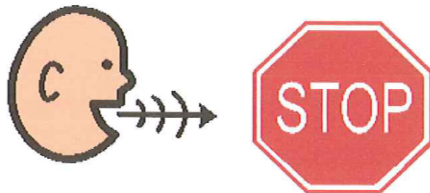
When we talk, you might feel upset.



It is OK to be upset when talking about someone who has died.

If you get too upset and want to stop, tell me. That is OK.

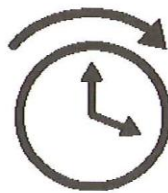
No one will be angry with you.



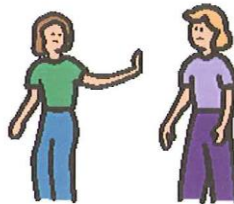
You can stop for a short time, like a break.



You can stop for a longer break, and we can talk again another day.



Or you can stop and not talk to me about it again.

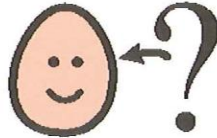


This is OK too. No one will be angry with you.

Remember – it is YOUR choice.

What will happen?

I will ask you some questions about when
.....died. I will ask you how you felt.



I will use a small recording machine to record what you
are saying. This means I can listen to the tape later to
remember what you said.



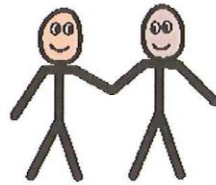
You can say you want to stop at any time. No one will be
angry with you.



We can talk at your house or at my office.



You can bring someone with you if you want.



Or we can talk alone, just the two of us.

When we are finished talking I will write you a summary of what you said, if you want.



Do you have any questions?



Appendix 4 – Letter to services



Robyn McRitchie
Trainee Clinical Psychologist
Department of Clinical Psychology
Learning Disability Service
Elmwood
Ashgrove Road
Aberdeen
AB25 3BW
Tel: 01224 557130

10th February 2010

Dear Service Manager,

I am a Trainee Clinical Psychologist in my final year of training, and as part of my training I have to undertake a research study. I am keen to carry out my research in the field of learning disabilities. In particular, I am interested in exploring the experiences of individuals with a learning disability when it comes to bereavement and grief. To date, research has shown that grief in the learning disabled population is often underestimated and misunderstood.

As someone who provides a service for individuals with a learning disability I would like to invite you to help facilitate my research. I am interested in identifying possible participants whom I could then invite to be interviewed on the topic of bereavement and grief.

Potential participants should fulfil the following criteria:

- Have a **mild** learning disability (as evidenced by historical information / present communication and/or functional abilities)
- Have **experienced bereavement** within the last 2 or 3 years (e.g. parent / sibling/ other relative / carer / keyworker / fellow service user)
- Be aged **over 18** years
- Be able to give **informed consent** to taking part (e.g. not have an Incapacity Certificate /not have a legally appointed Guardian)
- Be able to **communicate using speech** that is relatively clear and understandable (or can be interpreted by someone who knows them well)

The following **exclusion** criteria apply:

- Presence of an autistic spectrum disorder
- Presence of a dementia-type illness
- Anyone for whom participation may be unhelpful (e.g. currently experiencing bereavement-related difficulties)

I would be grateful if you could take time to consider whether any of your service users fulfil these criteria, and then contact me on the above telephone number with an estimate of potential participant numbers.

I will then be able to send out an invitation letter (sample copy enclosed) to those you have identified. This is a short document which uses accessible language and symbols that service users can read with assistance from care staff. It explains what participation would involve, and asks the service user whether or not they would like to meet with me to discuss things further.

Thank you for taking the time to read this letter and to consider facilitating my research. It is my hope that by exploring how individuals with a learning disability experience bereavement and grief, we can gain a better understanding of how to support individuals through what can be a difficult time. Your assistance at this stage is greatly appreciated.

Please feel free to contact me or to pass on my contact details to care staff or service users, should you/they have any questions or would like more information.

Yours sincerely

Robyn McRitchie
Trainee Clinical Psychologist

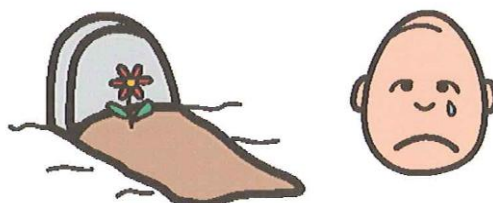
Invitation Letter

Hello. My name is Robyn McRitchie.



I am a student. I am doing a project on death.

I am talking to lots of people about their feelings when someone dies.



Do you know someone (special) who died?

Please put a ✓ in the correct box...

Yes

☐

No

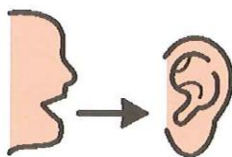
☐

Note to carer:

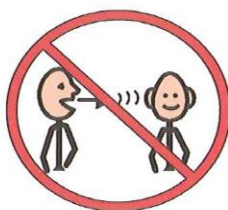
If no, thank you for reading this. Goodbye.

If yes, go to page 2.

Do you want to talk about it? I want to listen.



If you do not want to talk to me about it, that is OK.



It is YOUR choice!



Do you want to talk to me about it?

Yes

☐

No

☐

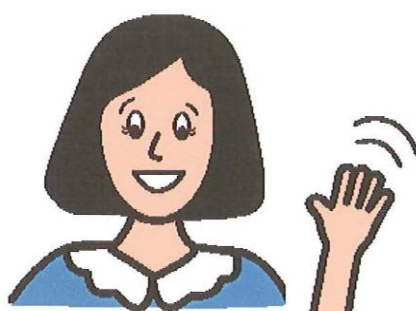
Note to carer: If yes, turn to page 4.

If no, turn to page 3.

You do not want to talk to me about it. That is OK!

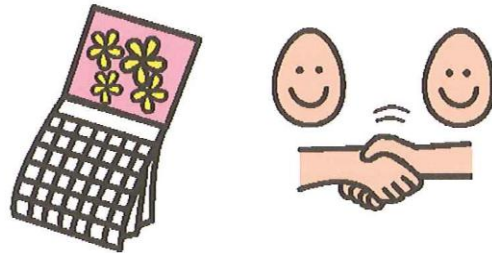


Thank you for reading this. Goodbye.



I am happy that you want to talk to me about it.

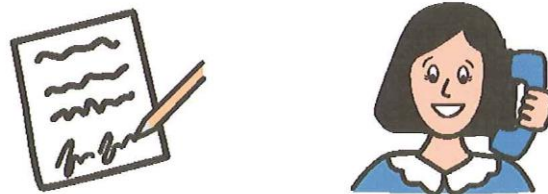
Tell your keyworker you want to talk to me and we can
organise a time to meet up.



If you have any questions, you can phone me.

My telephone number is: 01224 557 130

If I am not there, leave a message and I will phone you
back.



I am looking forward to meeting you and I am looking
forward to hearing what you have to say.

Appendix 6 - Questions to help establish capacity

- What is my project about?
- Why have I invited you to take part?
- Do you have to take part?
- What are we going to do together?
- Why will I be using a tape recorder?
- Who gets to hear our chat?
- What will we be talking about?
- What if you get upset?
- If you need a break what can you do?
- If you want to stop what can you do?
- We will meet next time for ½ an hour / an hour – what usually takes that long?

Appendix 7 – Consent form

Consent Form

My name is

I want | don't want to talk to Robyn about
when died.

I can | can't say I want to stop at any time.

What I say will | will not be kept private.

Signature: _____

Date: _____

Appendix 8 - Semi-structured interview questions

BEFORE

- Who was the person who died?
- How often did you see them?
- What were they like?
- Were they ill?
- Did you know they were ill?
- What did you think would happen?
- What was it like seeing them ill?

DURING

- Did you know they were going to die?
- When did you find out they were dead?
- Who told you?
- What was this like?
- How did you feel?
- What did you think?
- What were other people doing/saying?

AFTER

- What happened next?
- Did you view the body?
- What was that like?
- Did you go to the funeral/burial/cremation?
- What happened there?
- What was that like?
- What did other people do?
- What did you find the most difficult?
- What did you find was easier?
- What/Who helped?
- What/Who made things worse?
- What advice would you give to someone else in the same position?

TODAY

- What has today been like?
- What have you enjoyed?
- What have you not liked?
- What could have been done better?
- Would you do a similar project again?

Appendix 9 - Data coding sample

So do you remember what we're going to talk about today?

Something about my mother, or something, is that what you mean?

About your mother?

Yes.

Yeah, that's right. We're going to talk about what happened...

Yes I know what happened.

...when your mother died.

She, she died at an old age. She was 95 you see.

95!

Yes, a good age. She didn't die when she was young you see, just when she was too old. She just...something happened to her and she died.

Why did she die? Do you know?

Maybe just old age. Just old age. She never had much trouble but she just got a bit confused and everything since she got older.

Confused?

Yes, you see.

The screenshot shows a data coding interface. On the left is a list of codes: Notification, Support, Delayed emotional response with time, What was difficult, Interview experience, Lingering pride, Possible avoidance, Emotional response, Losses, Life goes on, What helps, Ritual involvement, Changes in roles and responsibilities, and Coding Density. On the right is a text area with several segments highlighted in yellow and pink. The yellow highlights correspond to the codes 'Causes of death', 'Unfairness of death', 'Fairness of death', and 'Predictors of impending death'. The pink highlights correspond to the code 'Reminiscence'.

Forgetting things?

Forgetting things, and then when she lost her hearing aid, she didn't remember where it was.

Ok.

She didn't know where it was. It got lost. Never found again.

Did you know she was not well?

Oh yes. Yes, she was sometimes in her bed. She stayed down at Town 1, you see. When our family all weren't able to look after her, she was, she moved down to Nursing Home 2, you see. Because, well, they could look after her better there. She was always falling at home. When we went to our beds she was up through the night and she wasn't able to walk about and she collapses. And we had to go and pick her up.

So she was having falls?

Yeah. And then they took her to Nursing home 1. But then they closed that down and she went to Nursing Home 2.

So she was at home but she wasn't managing.

No, not at home, she wasn't managing.

And she went to one place, then went somewhere else.

Yes, to Nursing Home 2. So she was staying there a long time. Sometimes she was fine and then times she was in her bed. Just with the, was tired. Wasn't wanting to rise.

And did you visit?



Yes I did. I went down to see her at night and entertained them with the MUSICAL INSTRUMENT. Down at...

Ah! You played your MUSICAL INSTRUMENT!

Yes I played the MUSICAL INSTRUMENT down there. I still do it yet. They told me when..."Now it won't harm your mother, now mother's died don't stop coming down, just keep coming." I was thinking of stopping because my mother died, you see, but they told me not to stop. I carried on.

Do you still go?

I still go. Even though my mother isn't there.

What's it like going there when your mum's not there?..... Does it...?

Well it was quite funny just to start with and I wasn't going to go. But I got used to it because I was in amongst a different crowd. And that kept you away from thinking about your folk and everything. It helped because other people were there and, you see, you forget about your mother and everything. And that helped me. Yes.

What about when you couldn't forget about mother? What was that like?

When I didn't have my mother?

When you went down to Nursing Home 2 and you would think about mum – what was that like?

Well, but other people, there was other people there.

Other people?

Yes.

- Notification
 - Causes of death
 - Unfairness of death
 - Support
 - Delayed emotional response with time
 - What was difficult
 - Fairness of death
 - Interview experience
 - Lingering pride
 - Possible avoidance
 - Predictors of impending death
 - Emotional response
- Losses
- Life goes on
- What helps
- Ritual involvement
- Changes in roles and responsibilities
- Reminiscence
- Coding Density

So they helped you?

Yes helped to forget about things you see.

Ok.

You just stuck to your MUSICAL INSTRUMENT and you forget about what's happened to your mother and that, you see.

Mmhmmm. What did they do to help?

Oh, I don't know about the helping bit. I'm not sure.

How did they help you forget?

Oh I don't know.....not sure about that one.

That's ok. So before mum...you knew mum was ill. Did you think she was going to die?

No I wasn't sure. It was just when I was working here, I was told she had died in the morning, the early morning.

So you were here when you found out?

Yes I was here when I found out, and X was here at the time. It was him that told me that my mother died. Died in the early morning.

What did X say to you?

Just that it had happened. He said "I want to talk to you." He said "Your mother has died this morning."



What did you say?

I got a bit of a shock.

A shock, yeah.

(Laughs)

What did it feel like? To get a shock?

I don't know, it just didn't.....

Did you cry?

No not really. Just worried about it.

Worried.

Yes.

What were you worried about?

(Laughs) Oh I don't know. I'm in a flat now you know.

Yes, you're doing very well. So when you heard that mum had died and **it made you worry...**

Yes to start with. But I fell away from that after a while.

You felt better about it after a while?

We just knew that she was an old lady and that, had it been somebody...if she'd been younger and had something wrong with her, we would have been more worried about her, maybe. But we just

Notification

Causes of death

Unfairness of death

Support

What was difficult

Interview experience

Lingering pride

Predictors of impending death

Losses

Life goes on

What helps

Ritual involvement

Changes in roles and responsibilities

Reminiscence

Coding Density

Emotional response

Possible avoidance

Delayed emotional respon

Fairm

knew she was getting old. And they were telling me that "Your mother maybe won't live long now because she's an old lady" you see.

Ok.

So after that I just stopped going to respite and went into my own flat.

So people had already told you that mum might not live very long.

No that's right. They told me that. They told me that at the respite, yes.

Was that good to know, or was that bad to know? Was it good that they told you?

Yes.

What was good about it?

Oh....

It's a difficult question...

I don't know. I'm not sure about that. I can't get round that one!

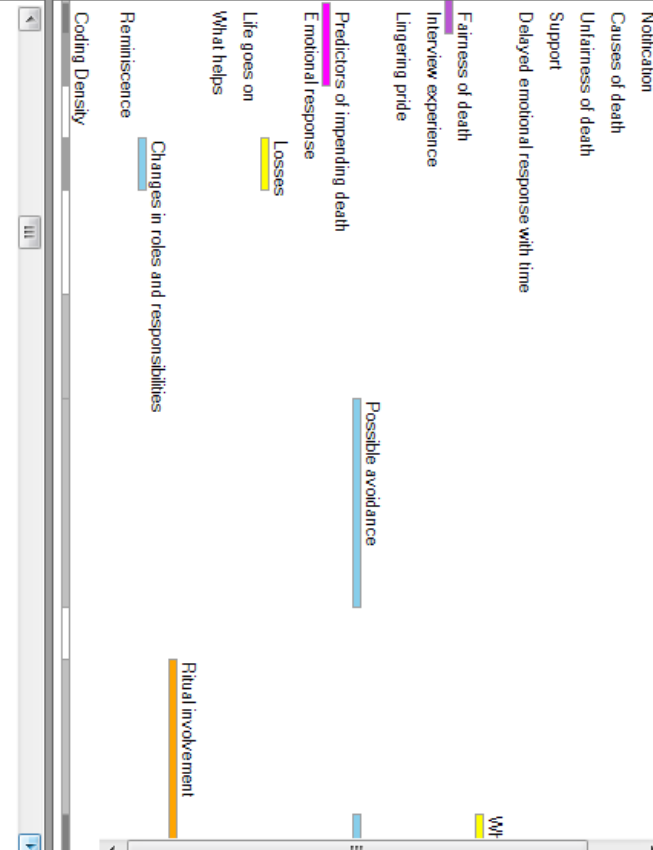
You're not sure. That's ok. After mum died, did you see her again?

Oh yes, I saw her at the rest rooms.

The rest rooms?

Yes when she was in a coffin-like thing. I saw her at the rest rooms.

You went to the rest rooms?



That's a lovely thing to do.

(Laughs)

So when you saw her in the rest room you gave her a hug?

No. That was when she was down at Nursing Home 2. She was in her bed.

Ah. You didn't give her a hug in the coffin?

NO!

Why not?

(Laughs) I'm not sure about that.

Did you touch mum, when she was in the coffin?

I might have done, I can't remember. Not really.

No?

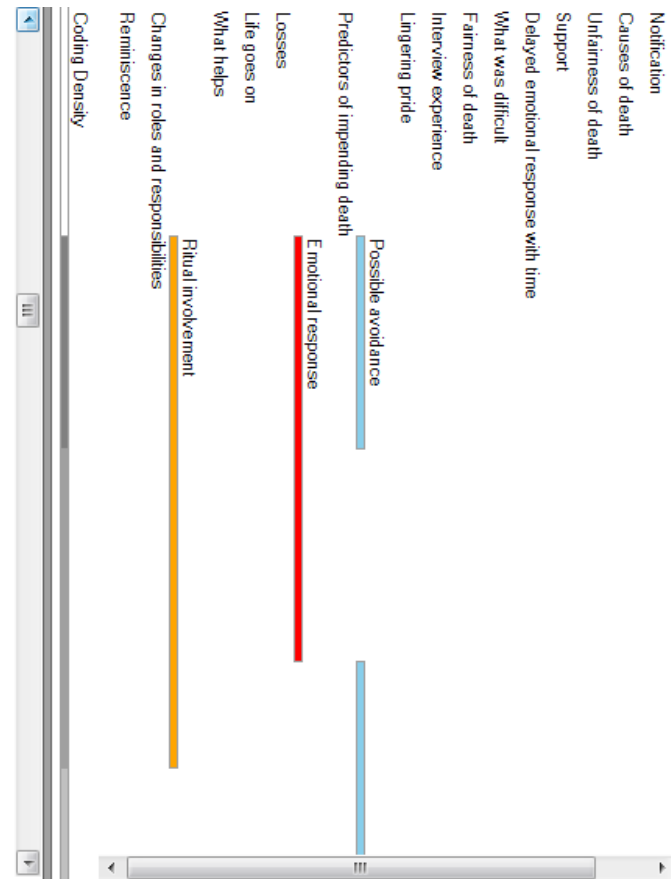
I didn't want to.

Was it... are you glad that you saw her in the coffin?

Oh yes. Yes.

Why?

(Laughs) That's a difficult question.



Ok.

I can't get my head round that one.

Don't worry. After you saw mum in the restroom, what happened next?

I think I just went away home again. Got out of there.

Were you upset?

Could have been. (Laughs) Yes I was upset, yes.

Were you crying? What made you upset?

I don't know, not sure.

It maybe just wasn't very nice to see mum when she wasn't up on her feet?

No that's right.

And was there a funeral?

Yes there was a funeral. Yes there was.

Tell me about that?

Well, I don't know. I'm not sure.

Did you go?

Yes I went to my mother's funeral. You see I had a cord down at the coffin. I had a certain



number. They call out your number when you're lowering the coffin you see.

You had a number?

Yes for lowering the coffin. I had to stand at the door of the church and shake hands with everyone when they came in at the door. With my brother.

Is there anything else you did at the funeral?

Not sure. No I don't know. I can't remember. Just went to the church.

And did they talk about mother?

Yes, the minister did. Talked about my mother and everything, yes. A story about her. What she did in her life when she was on the go.

Was that good or bad to hear?

Good. (Laughs)

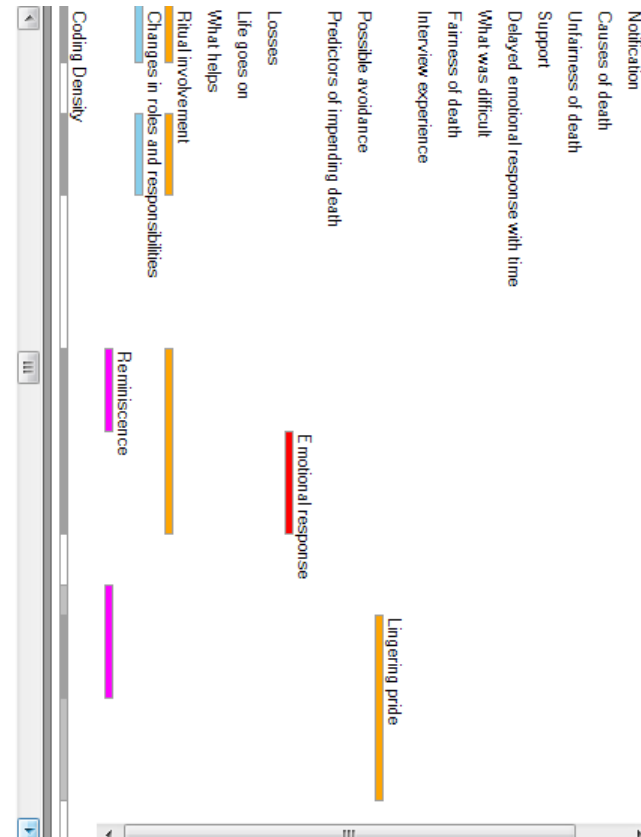
Yeah, I bet it was.

They told us what she did in the days that she was staying at home. She liked to knit. Did her knitting. She had a knitting machine and knitted jerseys with the 'Region Musical Instrument Club' on the jersey.

Very good!

Yes. That's not easy you know - putting it on.

I bet. And when you heard the minister talking about mum, how did it feel?



Notification

Causes of death

Unfairness of death

Delayed emotional response with time

What was difficult

Fairness of death

Interview experience

Lingering pride

Predictors of impending death

Emotional response

Losses

What helps

Changes in roles and responsibilities

Reminiscence

Coding Density

Support

Possible avoidance

Life goes on

Sad. Very sad.

Were people crying?

No not really. Just sad at what had happened.

And then you had a number to hold the rope.

Yes they called out your number and you came over and took a hold of the rope. I can't remember what number it was, but they call your number and you've got your number on a card, a ticket, that told you what number you had.

And when you were letting the rope down, what did that feel like?

Not too good. No.

What was bad about it?

(Laughs) Oh... I don't know. It was just sad. I don't know.

And was there anyone who helped you when you felt sad?

No, not really. They were just there beside me. No, no.

When you felt sad did anyone make you feel more sad?

(Laughs) I'm not sure about that.

And then after the funeral, after you let the rope down, the next day. **What happened the next day?**

Em...I don't know...I can't remember what I did...just went home.

He was a musical man too, he played the MUSICAL INSTRUMENT. I played along with him on the



MUSICAL INSTRUMENT.

Very good, a very musical family.

My brother plays the MUSICAL INSTRUMENT too, but he played before me and when I tried playing he thought I wouldn't be good. He said "You are going to be no use at playing the MUSICAL INSTRUMENT". But I just learned the music and he got a scare. "God!" he said. "You are better than I thought." He got a scare.

I bet he did! He thought you were going to be no good! He was wrong.

Yes he was wrong! I read the music and everything. I was better than he was.

What happened when dad died?

He had some kind of trouble - cancer. He was in his bed the whole day when we were outside and everything. He never rose that day because there was something wrong with him you see. He was up in bed for a long time that day, and then, when it got to about 8 o'clock, my mother said "God, I see a change in him now." Then after that he died in the bed.

He died at home?

Yes, in his bed.

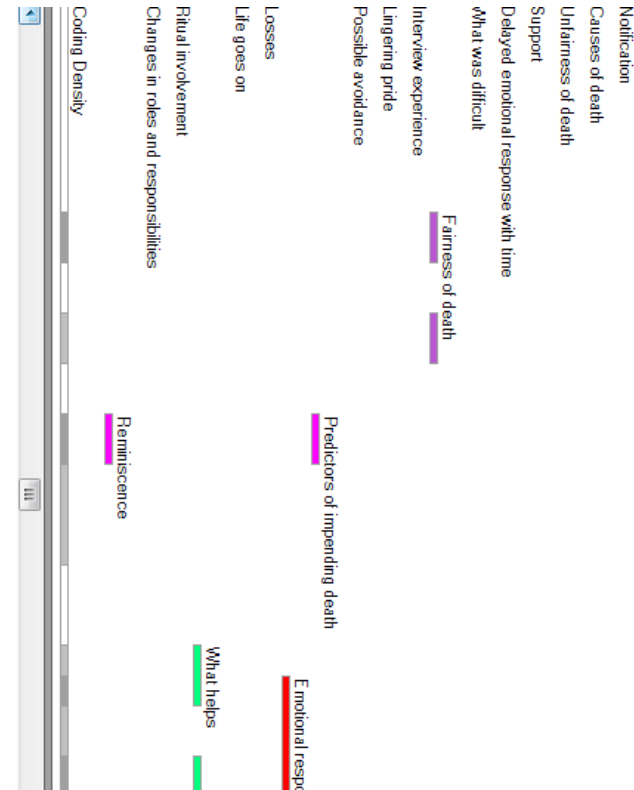
And you were there when he died?

Yes I was there. That was my father.

What was that like?

But I wasn't at home when mother died – I was working here. Because that was early in the

Notification	
Unfairness of death	
Support	
Delayed emotional response with time	
What was difficult	
Fairness of death	
Interview experience	
Lingering pride	
Possible avoidance	
Emotional response	
Losses	
Life goes on	
What helps	
Ritual involvement	
Changes in roles and responsibilities	
Reminiscence	
Coding Density	



morning.

Ok, so when dad died you were there. But when mum died you weren't there.

No I was at work.

When dad died in the house and you were there was there anything bad about that?

No, not really, because we knew that he had a trouble.

So you knew that he had been unwell.

Yes, we knew he had been unwell.

Ok, and what happened to mum when dad died?

Well she was ok back then, still walking about and everything.

Was she very sad?

No I don't know. Not sure. Just normal I suppose.

And if you could give someone advice - when someone dies, what helps? When someone dies, what helps you?

Well when my mother died they took me home from here, home to mother and father's old house so that it gave me comfort that day. I stayed there for a few days until you recover again. Then after I forgot about everything I came back to work again.

Ok, **so was it good to have a break?**

Yes it was. It let me recover from what had happened to my mother you see.

Good. And what did you do on your break?

Just stayed at home for a bit and then came back to work again.

Did anyone visit you when you were on your break?

Eh.....not really, no. Nobody came.

Were you just by yourself?

Well my sister would have been there. She was staying with my mother at the time.

So you went to stay with your sister.

Yes I stayed with her for a while, but she was going to be moving out of where my mother stayed, when my mother died. She was going to go to a house to stay by herself. Then when she went to live by herself I moved into my flat.

Right.

So I still go down and visit her now. And sometimes we'll go shopping together.

So before mum died, did you live with mum?

Yes I did. But before I worked here I used to work on a farm and I would just come home on the weekends to get my clothes washed, stay the weekend, then go back to the farm again.

Ok so during the week you stayed on the farm, and weekends you came home and lived with mum and sister.



Yes. Then when mother died my sister wanted to live in another house so she moved in by herself. But she only had one bedroom you see so I moved into my flat. And I still stay there. I'm happy there.

Was that good to move into your own flat?

It was. Because the people in there are nice to me.

They're nice to you? Oh that's good.

Nice people.

Did you miss living with mum and sister?

I suppose I did. But I have a carer that comes in to make my supper.

Ok.

I just make my own at the weekend.

I see.

She'll be coming in tonight to make my supper.

Ok. And now – do you miss mother now?

Not really. Not now. But I did to start with but I'm kind of used to it now. When you're in among other people you forget about what happened to your mother.

So to start with when you missed mother. What did you miss?

I don't know. That's a difficult question, that is.



Did you miss talking to mother?

Yes. Sometimes I talked to mother when she was living. Down at Nursing Home 2. And then the nurses would say "It's about time you went away home!" (Laughs)

They had to throw you out!

Yes, I wouldn't go home!

And did you miss your sister after you moved into your own flat?

No not really. I was always going back and forth to visit her anyway you see. At the weekends and that. I wasn't missing her that much because I'll sometimes phone her. Tell her about anything.

So if you missed her you could phone or you could visit.

Yeah.

What have you brought with you today?

Well someone told me that you would like me to bring a photograph of my mother so...look...that's my mother and my father, look. He's playing the MUSICAL INSTRUMENT there. And that's me.

That's you!

I was a younger boy at that time. (Laughs)

That's a lovely picture. How does it feel to see mother and father in a picture?

I just like ones that were taken when they were fine, together, back then. I think that was taken at their wedding anniversary or something. I have another one here...

Notification

Causes of death

Unfairness of death

Support

Delayed emotional response with time

What was difficult

Fairness of death

Interview experience

Lingering pride

Predictors of impending death

Emotional response

Losses

What helps

Ritual involvement

Reminiscence

Coding Density

Life goes on

Changes in roles and responsibilities

Poss

Oh that's an old one.

That's my whole family there.

Is this you?

Yes. And that's my brother, my oldest sister and then my youngest sister. That's who I phone. That's my mother and that's my father. They look different there, much younger. I remember a story about my father – my granny told me this story. When he had just newly married my mother and they were living upstairs at my granny's house. And my granny would shout up to my father "Come on down and eat your porridge or it'll get cold!" And he said "Well I like cold porridge." (Laughs)

He liked it!

Yes that's what he said! What a thing to say! My granny told me that story.

Do you look at these photos often?

Yes, because I have them in an album you see. I took them out of it to show you today.

Yeah. And does the album help?

Yes, looking at them, looking back at all the old people. Helps me remember. Because my granny and granda have died too you see.

So is it good to have an album?

Yes it is.

Whv?



Why?

To look back and see your parents and remember what happened to them. Look back at your parents.

Good.

It is, yes.

Is there anything else you want to talk about, about mother and father? Before mother died you saw her every weekend?

When I was working on the farm? No, once a fortnight when I came home to get my clothes washed. I saw my father as well.

What about when you were working here? Were you still living with mother?

Yes. You see it was my two uncles that had the farm and they died too, as well. So they rented the farm out and I didn't have a job. So I saw my social worker and my mother said "You'll maybe get a job at Day Centre 1." So my social worker took me up here and then I met the manager and he said "Come one out and see what I do." And that was the first time I met him. I had met his father before but not him. And he said to me "Well when do you want to start?" And I said "Well I can start right now!" He had thought I'd say tomorrow, but I said "Right now!"

So you got a job right away!

Yes I got a job right away! And I got to do the flowers and everything.

What do you remember about mother? What was she like?

Em...a nice kind of woman. (Laughs loudly) But we all had to behave ourselves because if we

- Notification
 - Causes of death
 - Unfairness of death
- Support
 - Delayed emotional response with time
 - What was difficult
 - Fairness of death
- Interview experience
 - Lingering pride
 - Possible avoidance
 - Predictors of impending death
 - Emotional response
- What helps
 - Ritual involvement

- Losses
- Life goes on
- Changes in roles and responsibilities
- Reminiscence

Coding Density

didn't it would make her fierce!

Oh, she could get fierce?

Yes, if you didn't behave yourself. There's no one to make sure I behave myself now! (Laughs) People ask "Are you behaving yourself?" and I say "No, I never behave myself now!" (Laughs loudly) I like a laugh. I get good fun working here.

Good stuff. Is there anything else about mother that you want to talk about?

Oh well, I don't know, I'm not sure. Well she liked to work outside, my mother.

Like you do!

Yes, like me. She liked working out, in amongst the hens and everything. She liked to go out into the woods and look for sticks as well. Get a few sticks and take them home for the fire you see. If we didn't gather sticks every day, then, if we left them outside till the next day, someone else would gobble them away with them!

Oh no!

Yes they'd take them away home with them!

Oh dear! Is it nice to talk about mother?

Yes, and my father had a flock of sheep and we would help him sort the new lambs into different fields.

Ok. When you remember about mother and father, does it make you happy or sad?

Well I'd say it makes me happy.

Notification

Causes of death

Unfairness of death

Support

Delayed emotional response with time

What was difficult

Fairness of death

Interview experience

Lingering pride

Possible avoidance

Predictors of impending death

Emotional response

Losses

Life goes on

Ritual involvement

Reminiscence

Changes in roles and responsibilities

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What helps

Good. What makes you happy?

Well I like a laugh and to have a bit of fun, maybe.

And today, talking about it with me - what has that been like?

I don't know.

Today when we've been talking has it been good or bad?

It's been good. I'd say it's been good because we've had a bit of fun with what we're saying.

What has been good to talk about? What have you enjoyed today?

I've enjoyed speaking to you about my family and everything. Yes, I've enjoyed that.

Is there anything you haven't enjoyed?

No. Not that I can think of, no.

Have you found it good to talk about mother and father?

It is, yes. It is good to talk to you about it. It brings them all back to life again when you talk about them. Brings it back again.

And that's a good thing or a bad thing?

A good thing. I would say that's definitely a good thing.

Would you like it if people talked about it more with you?

Yes, but I never worry about it. No.

Notification

Causes of death

Unfairness of death

Support

What was difficult

Fairness of death

Lingering pride

Possible avoidance

Predictors of impending death

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Good. Well, thank you very much, you've been really good to talk to.

So have you. You've been nice to talk to me.

Good, I'm glad you've enjoyed it.

I have enjoyed it, yes. I've enjoyed talking to you.

Good. Is there anything else you want to talk about, or are you ok to finish now?

Yes that's good. That was nice of you to talk to me. This has been a happy meeting. I like talking about my family. You have made me very happy today.

Appendix 10 – Saturation of main themes by participant

Master theme	Sub-theme	Alan	Beth	Bill	Jack	Jane	Jeremy	Katie	Keith	Kevin	Louise	Mary	Matthew	Norman	TOTAL
Core beliefs about life and death	Afterlife beliefs	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓	✓	11/13
	Causes of death	✓			✓	✓	✓	✓		✓		✓	✓	✓	9/13
	Fairness of death	✓		✓	✓	✓		✓		✓					6/13
	Life goes on	✓		✓	✓		✓	✓		✓	✓		✓		8/13
	Predictability	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓		11/13
Level of inclusion	Awareness of practices			✓		✓								✓	3/13
	Communication	✓		✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	11/13
	Notification	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	12/13
	Predictors of impending death	✓		✓	✓	✓	✓	✓	✓	✓			✓	✓	10/13
	Ritual involvement	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13/13
Continuing relationship with the deceased	Lingering pride	✓		✓	✓	✓	✓			✓	✓	✓	✓	✓	10/13
	Obligation	✓			✓				✓			✓		✓	5/13
	Reminiscence	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	11/13
	Yearning	✓	✓			✓	✓		✓		✓	✓	✓	✓	9/13
Lived experience	Changes in roles and responsibilities	✓	✓		✓	✓		✓		✓		✓	✓		8/13
	Emotional response	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13/13
	Exclusion		✓			✓	✓				✓	✓		✓	6/13
	Helplessness	✓	✓			✓	✓			✓		✓		✓	7/13
	Losses		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		10/13
	Support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	13/13

